



National Indigenous Palliative Care Needs Study

Final Report | April 2003



THE NATIONAL
PALLIATIVE CARE
PROGRAM

Prepared for the Australian Government
Department of Health and Ageing
by Kate Sullivan and Associates Pty Ltd

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Report by
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Glossary

ACAT	Aged care assessment team
ACCHS	Aboriginal Community Controlled Health Service. This term is used when referring to general policy issues or sometimes when referring to this group of services globally. In other places we use the term AMS because it is the term which health consumers and service providers commonly use in speaking about their local ACCHS.
AH&MRC (NSW)	The Aboriginal Health and Medical Research Council (NSW)
AHLO	Aboriginal Hospital Liaison Officer (see also ALO)
AHREC	The Aboriginal Health Research Ethics Committee of South Australia
AHW	Aboriginal Health Worker
AIDA	Australian Indigenous Doctors' Association
AIN	Aid In Nursing
ALO	Aboriginal liaison officer (usually based in hospital), usually called KLO (Koori liaison officer) in Victoria (see also AHLO)
AMS	Aboriginal Medical Service (This refers to the local ACCHS. We generally used this term because it is the term that most participants and interviewees used.)
Anangu	Aboriginal people, central Australia
AMSANT	Aboriginal Medical Services Alliance Northern Territory
AP lands	Anangu Pitjantjantjara Lands
Bama	Aboriginal people (North Queensland)
Blue Care	Blue Care Nursing Service (Queensland)
CAAC	Central Australian Aboriginal Congress
CACP	Community Aged Care Packages
CALD	Culturally and Linguistically Diverse
CAPD	Continuous Ambulatory Peritoneal Dialysis
CATSIN	Congress of Aboriginal and Torres Strait Islander Nurses
COPS	Community Options Program
CME	Continuing Medical Education
CNC	Clinical Nurse Consultant
CNS	Clinical Nurse Specialist
DCS	Domiciliary Care Service
EPC	Enhanced Primary Care
EN	Enrolled Nurse

GP	General practitioner, doctor
GPAC	General Practice Advisory Council
Green Nurses	Domiciliary nursing service (North Queensland)
HACC	Health and Community Care worker
HOP	Hospital to home Pathways (Adelaide)
HOPS	Homemakers and Old Peoples Services (Alice Springs)
ICAN	Indigenous Clinical Advisory Nurse
Koori	Aboriginal person (in general use in NSW and Victoria)
maparn	Traditional healer (northern Western Australia)
Murri	Aboriginal person (Queensland)
NACCHO	National Aboriginal Community Controlled Health Organisation
<i>ngangkari</i>	Traditional healer (Central Australia)
NHMRC	National Health and Medical Research Council
Noongar	Group name for Aboriginal people of south-west Western Australia including the traditional inhabitants of Perth; also spelt Nyoongar and Nyoongah
NPCS	National Palliative Care Strategy
NPYWC	Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council
OATSHI	Office of Aboriginal and Torres Strait Islander Health
PATS	Patient Assisted Travel Scheme
PCA	Palliative Care Australia
PHCAP	Primary Health Care Access Program
QAIHF	Queensland Aboriginal and Islander Health Forum
RCIADIC	Royal Commission into Aboriginal Deaths in Custody
RDNS	Royal District Nursing Service (South Australia and Victoria)
RFDS	Royal Flying Doctor Service
RN	Registered nurse
Silver Chain	Silver Chain Nursing Service (domiciliary nursing service Western Australia)
St Luke's	Domiciliary nursing service (Queensland)
TAFE	Technical and Further Education
VACCHO	Victorian Aboriginal Community Controlled Health Organisation
VET	Vocational Education Training
WAAHIEC	Western Australian Aboriginal Health Information and Ethics Committee
Wongi	Aboriginal people of central desert region, Western Australia.

Executive summary

a) Background

The Australian Government's National Palliative Care Strategy, adopted in October 2000, recognises the need for services which cater sensitively and flexibly for the needs of Aboriginal and Torres Strait Islander peoples. The strategy has the potential to improve the delivery of services to Aboriginal and Torres Strait Islander communities (urban, rural and remote) by concentrating on three broad areas:

- the development of awareness and understanding in the community and the professions;
- the development of appropriate standards and tying resource allocation to best practice; and
- the building of partnerships between those delivering services and communities, and facilitating coordination of and access to services

The purpose of this study was to provide an understanding of:

- what palliative care services are currently being delivered to Aboriginal and Torres Strait Islander people;
- what the real needs of Aboriginal and Torres Strait Islander clients are (whether they are in urban or remote areas);
- how well current services meet the needs (especially in relation to culturally appropriate service delivery and ability to access appropriate services); and
- how the National Strategy can be focussed to ensure that its aims are achieved in relation to Aboriginal and Torres Strait Islander people.

b) Initial scoping and field methodology (Chapters 1 and 2)

The project commenced with an initial scoping period during which the relevant branches of all State and Australian Government health departments and other key stakeholder groups (including the community controlled health sector) were contacted for information regarding Indigenous palliative care. Telephone interviews were conducted with service providers that had been identified as providers of palliative care services to Aboriginal and Torres Strait Islander clients. The outcome of the initial scoping was the discovery that there were very few Indigenous specific services or initiatives in palliative care. It was decided to canvass mainstream service providers to discover the rate of Indigenous access to their services.

After the initial scoping, the study turned toward the task of identifying the needs (including unmet needs) of Aboriginal and Torres Strait Islander palliative care patients and their families.

Field locations were selected that were representative of either those areas in which we had had reports of 'good practice' (which in this case usually meant 'any practice reported as having Indigenous clients') or areas of high Aboriginal and/or Torres Strait Islander population where it appeared there were few palliative care services. One location was also selected for the development of draft regional guidelines on the basis that this had been requested by the Aboriginal medical service (AMS) in the area.

Field methodology was developed and proposed to relevant ethics committees. In New South Wales, a delay in receiving a response from the ethics committee necessitated a change in field methodology (see further Chapter 1, Sections 1.6.3 and 1.6.4).

In each location to be visited, palliative care service providers and the community controlled health organisation and/or local State funded Aboriginal or Torres Strait Islander health service were contacted by letter and followed up by telephone. Aboriginal and Torres Strait Islander organisations were asked if they were willing to participate and if so to nominate the form in which they wished to receive feedback. (The project already had a newsletter component.) All responded favourably to our request to participate in the field work, though none were specific about the nature of the feedback they wanted. In some areas we responded to informal requests for advice or for assistance with funding applications. After completion of the fieldwork it was decided that uniform and general feedback for all the participants was needed and so a special, more detailed edition of the Newsletter (number 3) was produced for this purpose. Multiple copies were supplied to all the areas we had visited.

This report lists the geographic locations where fieldwork took place but the reporting protects the identity of communities and individuals as was required in our methodology.

Chapter 2 documents what the study discovered about how and where palliative care services are delivered around Australia.

c) Socio-economic contexts (Chapter 3)

Chapter 3 outlines key issues of importance (socio economic and traditional contexts) for policy makers and palliative care service providers and Chapter 5 examines how some of these issues affect service delivery in the various settings of care.

Service providers and policy makers in palliative care need to understand the socio-economic realities of many Aboriginal and Torres Strait Islander clients, and the impact of historical factors in Aboriginal and Torres Strait Islander peoples' views about health services. The importance of self-determination and the existence of culturally appropriate services, in particular those provided by Aboriginal community controlled health services (ACCHS), should be recognised. Mainstream service providers should be sensitive to the needs of clients, modifying their service provision in consultation with local people, and try to engage with existing Aboriginal and Torres Strait Islander health providers to provide an integrated service.

d) Communication (Chapter 3)

Good communication is central to understanding the palliative care client's wishes and needs:

Palliative care respects the dignity of the person who is dying, and is based on the person's needs and wishes, with attention to the specific needs of different cultural and religious groups. [extract from the definition of palliative care in the National Palliative Care Strategy (2000)]

The barriers to good communication with Aboriginal and Torres Strait Islander clients identified in the study included both language and non-language barriers. Differing values and beliefs create hidden difficulties. Understanding that complex cultural relationships exist and impact upon who should or

should not be involved, for instance in care or decision making, is critical. Both cultural brokers and language interpreters are needed to deliver good palliative care. In many places in Australia there are Aboriginal and Torres Strait Islander people who do not speak English but there are few, if any, interpreter services available to service providers. This need applies equally in capital cities as in remote areas or remote regional centres. City hospitals in Adelaide and Perth, for example, often treat Aboriginal patients from remote areas who do not speak English. Interpreters working in palliative care require some orientation in palliative care philosophy and practice.

Cultural awareness training specifically designed for palliative care workers is needed but should not be regarded as a substitute for employing (or 'buying in' the services of) Aboriginal and/or Torres Strait Islander staff.

e) Traditional issues (Chapter 3)

Many Aboriginal and Torres Strait Islander people use traditional medicine to varying degrees. Facilitation of access to traditional medicine and traditional healers where requested, and ensuring that protocols are in place to discover and accommodate end of life cultural practices should be usual palliative care practice.

Service providers must be sure that actions taken or permissions sought will not have cultural repercussions, either for family or community members or for themselves. They should work with local cultural interpreters to find solutions. Examples are given of traditional practices such as avoidance practices and ascribing 'blame' which, whilst not relevant to all Aboriginal and/or Torres Strait Islander communities, are very serious issues which underline the need for effective cultural awareness training and access to knowledgeable Aboriginal or Torres Strait Islander staff. It is critical that practices and protocols be checked for cultural safety and that they allow for case by case variation and advice.

It is clear that many doctors make assumptions based on a limited understanding of cultural issues. Without the advice of a cultural advocate they may make assumptions which reduce the choices of care available to their clients. We discovered misconceptions about pain, about ready acceptance of death, and about speaking about death. These all have serious consequences for Aboriginal and Torres Strait Islanders peoples' ability to access palliative care and to receive a high standard of palliative care service.

f) Access to Palliative Care Services (Chapter 4)

A key finding of the research is that comprehensive data on the rates of Indigenous access to palliative care services does not exist. Most palliative care service providers do not have access to data on the Indigenous status of their clients as this is usually recorded 'upstream' of their admittance to a palliative care program. Anecdotal evidence also suggests that the recording of clients' Indigenous status may not be accurate because data recorders make assumptions, rather than ask the question.

These issues aside, there is enough information to be sure that people of Aboriginal and Torres Strait Islander descent are not accessing palliative care services at a rate commensurate with their representation in the population, and especially given their high mortality rate. The reasons for this are explored in Chapter 4 and include the following:

- lack of availability of services in some areas where Aboriginal and Torres Strait Islander people live;
- lack of referral by specialists, GPs and doctors in ACCHS;

- lack of knowledge about palliative care services on the part of Aboriginal and Torres Strait Islander health service providers and community members;
- a number of perceived barriers including:
 - past experiences of the health system,
 - dislike of hospitals and hospices,
 - lack of Aboriginal and Torres Strait Islander staff in mainstream services,
 - lack of support at the time of referral, including the lack of involvement of cultural advocates in discharge planning,
 - the cost, and perceived cost, of palliative care,
 - attitudes (of some Aboriginal and Torres Strait Islander peoples and some doctors) to speaking about death,
 - attitudes and perceived attitudes of mainstream service providers that provide services to clients at home.

Probably the most significant factor influencing access (or lack of access) to palliative care services is the question of referral.

In general, Aboriginal and Torres Strait Islander clients are either not referred to palliative care at all or are referred at a very late stage of their illness.

In part this is due to the underlying health status of Indigenous people, however lack of referral and late referral and are also due to assumptions of doctors (GPs, AMS doctors and specialists) about whether Aboriginal and Torres Strait Islander clients will want to be referred to palliative care services. Many GPs have a poor understanding of what palliative care is and how it may benefit clients, and/or how they can be involved in providing an integrated service. It appears that many doctors make assumptions that patients will not want to be referred to mainstream services, yet most AMSs have neither the resources nor staff with the skills needed to provide palliative care.

If referrals are made, but are not supported by cultural advocacy and/or the participation of Aboriginal and Torres Strait Islander staff, then they may not be taken up.

As a result of late referrals, service providers and families do not have the time needed to establish good relationships, which are essential to good service delivery and to 'good word of mouth' about palliative care.

If clients are not referred, or are referred late, they do not receive the information they need to be able to make informed choices about how or where they wish to care or be cared for. As a result Aboriginal and/or Torres Strait Islander patients are more likely to die in hospital, which may not be their wish.

These issues point to three main areas for attention: staffing, attitude change and information. Increased Aboriginal and Torres Strait Islander staffing in palliative care services, the provision of cultural brokerage services at key points such as discharge and referral, and effective cultural awareness training should improve access rates.

Effective information strategies are needed, both to increase the understanding and awareness of community members about palliative care and to educate GPs, AMS doctors and specialists. Information strategies need to be targeted:

- among Aboriginal and Torres Strait Islander peoples there is a need to change the image of palliative care from being about 'being put in a hospice' or being only for cancer patients, to developing an awareness that palliative care can support families to look after their own at home;

- for GPs and AMS staff, there is a need to re-position palliative care so that they appreciate that rather than handing over the care of their patient to strangers, they can continue to be involved as a member of the palliative care team;
- for mainstream palliative care service providers there is a significant need for effective cultural awareness training (including information about Aboriginal and Torres Strait Islander service providers) which can deliver competence in cross cultural practice. This would equip service providers with the skills to build relationships with these groups so that they can work together to provide the best support to Aboriginal and Torres Strait Islander clients.

‘Word of mouth’ was widely acknowledged as the most effective way of providing information about palliative care to Aboriginal and Torres Strait Islander communities and should be backed up by clear written materials which are specifically targeted to an Aboriginal and Torres Strait Islander audience.

Another issue that is critical for Aboriginal and Torres Strait Islander clients’ ability to access palliative care is the recognition that diseases other than cancer, such as chronic obstructive pulmonary disease, heart failure and renal failure, may require referral for palliative care. Whilst these diseases do not always present symptoms that require the kind of management usually associated with palliative care (i.e. they may not be painful until very late in the disease), clients and their families may well need timely psychosocial support which is part and parcel of palliative care. These conditions are very frequent amongst Aboriginal and Torres Strait Islander populations.

g) Planning and delivery of care (Chapter 5)

Chapter 5 documents findings in relation to care planning and delivery of care and presents suggestions for how the problems that were reported might be addressed. This chapter focuses on the setting of care and examines the significance of the place of death to Aboriginal and Torres Strait Islander peoples. Discharge planning and assessment, bereavement counselling, medication and pain management, equipment and palliative care providers’ access to specialist advice are also examined in this chapter.

i) Attitudes and expectations

An issue that is fundamental to access to services and to the quality of care is the underlying experience of and attitude of Aboriginal and Torres Strait Islander people towards the health system and towards non-Indigenous bureaucrats and service providers. Past experience has a powerful impact on whether Aboriginal and Torres Strait Islander people will be willing to accept referrals to palliative care.

In general, Aboriginal and Torres Strait Islander people strongly dislike, distrust and fear hospitals and non-Indigenous strangers coming to their homes. Informants said that in their past experience, such strangers were usually police or ‘the welfare’.

Mainstream service providers should acknowledge these attitudes and the historical reasons for them. ACCHSs exist in order to overcome some of these difficulties and to allow community control of health service delivery. ACCHSs should be invited to become a central part of the specialist palliative care network and/or palliative care service providers should put their specialist skills at the disposal of these units, especially where they have mutual clients.

Service providers, in turn, hold attitudes which affect their behaviour towards Aboriginal and Torres Strait Islander clients. Many have never met or spoken with an Aboriginal person or Torres Strait

Islander and know little, or nothing, about Aboriginal and Torres Strait Islander health services. Unfortunately, many are perceived as highly judgemental by Aboriginal and Torres Strait Islander people. Most, for example, are unaware of complex family relationships or the group nature of many Aboriginal households and do not understand the implications of these when home visiting. Many would not feel comfortable in the often over-crowded conditions of many Aboriginal and Torres Strait Islander households. Concerns about hygiene and personal safety (both perceived and real) were reported. For their part, we were told that many Aboriginal and Torres Strait Islander people feel 'shame' when non-Indigenous strangers visit their home.

ii) Relationships

The attitudes and expectations of clients and service providers have very real significance for discharge planning and assessment and care planning. The importance of the referral process and the need for cultural advocacy at this time have been mentioned above.

In parallel with the need for supported referrals is the need for the development of trust between clients and service providers. Development of trust requires the development of a relationship. In many cases there is not enough time for this relationship to develop because of late referral.

Service providers working with Aboriginal and Torres Strait Islander clients should start to develop relationships with the community by beginning a dialogue with Aboriginal and community organisations (including health and home care providers). They need to establish their 'credentials' in the community first to pave the way for meeting clients and families. Being introduced or recommended by a community member is an essential first step to forming a relationship and is particularly critical where time is short.

iii) Discharge planning and assessment

There is a need to develop care pathways for palliative care clients which ensure consistent involvement of the palliative care team, a cultural advocate¹ (Aboriginal Hospital Liaison Officer [AHLO], Aboriginal Health Worker [AHW] from AMS, or Indigenous staff of the service provider) and appropriate family members in discharge planning.

A question about Indigenous status should be asked on admission as a palliative care client (with an explanation of why it is being asked). Assessment should not take place without the participation of appropriate Indigenous staff. Assessment processes should try to avoid a stream of individual service providers and may need to be done over several visits as relationships develop. The location of the assessment (including the place it is done in the home) and the language and listening skills used are crucial. Understanding the relationships of family members and realising that roles within the family may be culturally determined are also critical. The main carer may not be the decision maker. Service providers should work with Indigenous staff and/or community advisers to develop effective assessment processes for their particular situation.

iv) Access to cultural specialists

Service providers should ensure that they have ready access to and funding for a cultural specialist and should develop ongoing relationships with local Aboriginal and Torres Strait Islander health and community organisations.

¹ Unless this is expressly rejected.

v) Place of death

Issues about where people would prefer to die are vitally important to Aboriginal and Torres Strait Islander people and to the delivery of good palliative care. (See Chapter 5, Section 5.3)

During the fieldwork, community members and AHWs were interviewed about whether there was a 'right' place for someone to pass away, and if so whether there were problems in achieving this. Two major issues were explored. Firstly, there is the issue of the desire of Aboriginal people and Torres Strait Islanders to return to their country or home community to die and whether (and how) this can be accommodated. There is also the question of where the person should pass away within that country, town or community, and whether it should be at home or in the clinic, hospital or hospice.

For many people the importance of 'getting home to country' is the highest priority. This issue has been well documented and most service providers are aware of it, though there are still many reported instances of people being sent from remote areas to city hospitals for unnecessary treatment or treatment that will reduce their chance of passing away in their own country. This occurs because of inadequate information and a lack of informed choice on the part of the patient. In some instances patients may have preferred to stay in their own country with a reduced level of care or without treatment.

The key issue, is that rather than taking a decision about what they believe is in the best interest of the patient, health care professionals should assist the patient and family to decide what is best for them and should try to find ways to support that decision.

In many places it was reported that patients and their families would prefer the person to die at home, but few actually achieve that. Even in cases where a person has been cared for at home throughout their illness, they are likely to go to the hospital suddenly, at the final stage. Several reasons why this occurs were explored, including the capacity of the family to care for the patient, fear of the unknown, concerns about pain, not being ready to let go of a loved one, fear about spirits of the deceased, the desire to avoid the cultural requirement to vacate the home after a death and not wanting to be in proximity to the dying person for fear of 'blame' or payback.

Socio-economic contexts, traditional obligations and a mistrust of the health system combine to create significant dilemmas for families of palliative care clients. A key issue for both urban and remote peoples is that these matters, especially place of death, should be discussed early enough and with better information, so that clients can be clear about what they want and know that it can be made to happen. There was general and strong agreement that the place of death should be decided by the individual and their family.

Other implications for policy makers and service providers include: finding solutions to cultural dilemmas by provision of appropriate 'neutral' places where people can pass away with their family around them (several are suggested, see *l) Good practice* below); advocating on behalf of clients to get them home and getting the best service for them once they are there; improvement of hospital and nursing home facilities; and putting in place tracing systems in hospitals so that if the client is admitted to the emergency ward at the final stage, the staff will know that they are a palliative care client and will not give inappropriate treatment (see Chapter 5, Section 5.9.3).

h) Settings of care (Chapter 5)

Specific suggestions are made to address the shortcomings of delivery of care to Indigenous clients at home (see Chapter 5, Sections 5.4.1 and 5.4.2), in hospitals (Section 5.4.3) and in hospices (Section 5.4.4), and in nursing home and aged care facilities (Section 5.4.5). The importance of the continuity of care between the various settings as circumstances change is raised.

i) Care at home

Care at home was the preferred option of most people we spoke with. Issues identified to improve this included:

- service provider visits should be made in the company of Aboriginal and Torres Strait Islander staff;
- taking the time (and having the skills) to establish a relationship;
- competence in cross cultural communication and practice;
- being sure to establish who are the decision makers in the household;
- coordinating and reorganising services to reduce the number of strangers coming to the house;
- providing appropriate information on a range of issues and delivering these both verbally and in written form; and
- maintaining confidentiality and being discrete.

Having enough respite care services available to give carers a break is critical to most families' capacity to care at home.

The most appropriate role for the palliative care worker will be determined by the context in which they are working. For home based care, the model that best accorded with what Aboriginal and Torres Strait Islander informants said they wanted was to act as a coach to support and train the family so that they could undertake the care.

ii) Hospital and hospice

Hospitals are often seen as places of death rather than of healing by many Aboriginal and Torres Strait Islander people, and many communities are acutely aware of relatively recent racist practices, such as segregated wards, and labelling of cutlery and linen for Aboriginal patients (see Chapter 5, Section 5.4.4).

Few hospitals employ any Aboriginal or Torres Strait Islander staff except for an Aboriginal Liaison Officer (ALO) and these staff often described their experience as one of overwork and isolation. ALOs are rarely members of the palliative care team and generally do not participate in discharge planning of palliative care clients.

Few hospital staff receive adequate cultural awareness training and in regional hospitals the high staff turnover is particularly problematic, especially as there is a high use of agency staff and foreign nurses on temporary work visas who have no experience or understanding of Aboriginal clients and cultures.

We were told that attitudes and practices in hospitals were changing so as to be more accommodating to Aboriginal visitors and customs; for example some hospitals now permit smoking ceremonies to cleanse a room after a death. There remain many problems, however. The sterile and alienating environment, air conditioning, unfamiliar food and lack of accommodation, access to the outside and even enough space

for visitors who wish to be with the person who is dying or after death, are all barriers to the delivery of high quality, appropriate palliative care. Most hospitals do not have protocols to ensure that cultural practices and needs can be accommodated.

In contrast, interviewees who had had experience of a hospice for pain management or terminal care of a family member were very satisfied with the facilities and with staff attitudes. Many people interviewed thought that palliative care was synonymous with placing someone in a hospice and said they would not want to do that, however in two regions where familiarisation visits had been conducted, community attitudes had changed considerably and community members had begun to make greater use of the hospice as a result.

iii) Aged care and nursing homes

Indigenous specific aged care facilities and nursing homes play an important role in providing residential facilities for Aboriginal and Torres Strait Islander people who cannot be cared for at home by their families (see Chapter 5, Section 5.4.5). In some places, they employ a high percentage of Aboriginal and/or Torres Strait Islander staff (in some cases more than 50%). They offer a level of cultural comfort for residents that makes such facilities a valuable alternative to home care.

The quality and availability of palliative care in these facilities varies considerably, due in some cases to a lack of trained staff or lack of access to palliative care specialists. In some instances there is little or no relationship between these facilities and local palliative care service providers.

There are also some structural barriers to the provision of palliative care in these facilities. For example, regulations about administration of medication (and funding issues) may prevent a patient from staying in an aged care facility and receiving appropriate medication. Similarly, funding restrictions and the high cost of treatment at the terminal stage of illness may result in patients being transferred to a hospital at this stage.

Although most try to comply with cultural preferences associated with the end of life, in some regions the concern that others will be unable to occupy a room or use the facility after a death there is often managed by the transfer of patients to hospital at the final stage of their illness. As a result, patients may not be able to pass away in the place that has become their home. It is unclear whether the patient's wishes are consulted or respected where this occurs.

There are some regions, including major population centres such as Perth, where there are no Indigenous specific aged care facilities or nursing homes. This study did not investigate the delivery of palliative care to Aboriginal and Torres Strait Islander people in mainstream aged care facilities and nursing homes, but it would be expected that similar concerns would exist in relation to the delivery of culturally appropriate care.

iv) Need for medically supported hostels and palliative care for itinerant people

In cities such as Perth and Adelaide and in Alice Springs, a need was identified for medically supported hostels for short term accommodation of Aboriginal and Torres Strait Islander palliative care clients visiting for medical treatment (see Chapter 5, Section 5.4.6).

There is a need to develop strategies and funding arrangements to allow delivery of palliative care services to all people in the setting of their choice. This should include itinerant or homeless people who need palliative care and symptom management.

v) Counselling and bereavement care

Chapter 5, Section 5.5 discusses the availability and use of bereavement care services. There are very few appropriate services available for Aboriginal and Torres Strait Islander clients. It examines the special needs of Aboriginal and Torres Strait Islander people because of the burden of unresolved grief that most carry as a result of losses through dispossession of land, culture and identity, as well as the high mortality rate within their families.

The section examines how people grieve, and reports what people said they wanted. The need for early counselling, trained Indigenous counsellors and support for cultural protocols is most critical. Barriers to delivering bereavement services are examined and some areas of innovation and good practice are reported (Section 5.5.6).

A number of areas of need were identified, including needs for: more trained Aboriginal and Torres Strait Islander psychologists and counsellors; post graduate AHW training in grief and loss counselling; support groups; Aboriginal and Torres Strait Islander palliative care workers to be included as part of the palliative care team to ensure that early counselling takes place; greater emphasis on early referral; and recognition of the practical role in bereavement care played by Aboriginal and Torres Strait Islander staff assisting in funeral preparations. It is suggested that some mental health or counselling training for AHWs who assist with funeral preparations would augment their capacity in this vital role.

This section also identifies the need for more research into the best approaches to grief and loss for Aboriginal and Torres Strait Islander communities and for appropriate counselling and debriefing for Aboriginal and Torres Strait Islander health professionals who carry a particular burden with respect to grief and loss.

vi) Pain management, medication and equipment

The major issues here relate to how Indigenous people experience pain, the need for information about pain management, and the cost and perceived cost of medication (see Chapter 5, Section 5.7). Many Aboriginal people and Torres Strait Islanders cannot afford the dispensing fees, let alone the cost of medication which is not available on the Pharmaceutical Benefits Scheme. People often go without medication to pay for other family needs.

There were many reported cases of doctors prescribing inappropriate medication, that was either not the most suitable for symptom management, or that would not be available or be able to be administered when the patient returned home. There were numerous stories of clients arriving home in remote communities with prescriptions for medication that was unavailable in the community.

There are many issues of concern about the use of morphine. Many Aboriginal and Torres Strait Islander people are fearful of morphine and there are apparently many misunderstandings about its use. There are also safety and security issues about access to this drug by palliative care clients. Issues concerning equipment shortages are reported in *n) Funding and resources* below.

vii) Access to palliative care specialists

Access to symptom management specialist advice can be critical. Many services are now set up so that specialist doctors or nurses provide consulting services. In many places, palliative care advice lines exist for doctors and/or nurses, however these are not always well known and are often not used by GPs and

AMS doctors. Advice lines and personal networks are especially valuable to nurses working in relative isolation in remote communities or small towns. Palliative care providers state however that it is not the lack of advice opportunities that presents a problem, but rather GPs who do not *recognise* that they need advice.

Clients' access to after hours and weekend advice varies enormously but where it is available it is greatly appreciated. After hours emergency numbers are only useful to Aboriginal and Torres Strait Islander clients if they have a telephone or can access one.

Some implications are:

- the existence of palliative care service and advice lines should be marketed to GPs and AMS doctors;
- service providers should keep in mind that Aboriginal and Torres Strait Islander clients may not have telephone access and should either advocate for phone access on their behalf or set up emergency procedures that do not rely on phones;
- funding structures should be examined to allow for the funding of telephones for palliative care clients who otherwise would not have them;
- service providers should budget for the employment or brokering in of Aboriginal and/or Torres Strait Islander cultural specialists who could be on call to provide advice.

i) Workforce issues (Chapter 6)

Traditional healers should be seen as an important adjunct to palliative care services where families want this care. Funds should be available to facilitate access to healers if required.

Aboriginal Hospital Liaison Officers should participate in palliative care teams and in discharge planning. Currently, they are usually not involved.

- If ALOs were to be more involved in palliative care support and liaison roles, more would need to be employed or they would need to work more hours; they should also receive some medical training (AHW, Enrolled Nurse [EN] or Registered Nurse [RN]), because of the need for medical advocacy, as well as palliative care training.
- All ALOs should receive basic training in the nature of palliative care and the services available in that field.
- Roles, job descriptions, workloads, staffing levels, working conditions and qualifications should be examined to prevent exploitation of these workers and to ensure that Aboriginal and Torres Strait Islander clients receive the best service possible.
- ALOs should be better supported through formal supervision and emotional or counselling support.

Aboriginal and Torres Strait Islander Health and Community Care (HACC) workers play a large role in delivering palliative care to Indigenous clients, although this is often informal. The skill and knowledge of HACC workers in delivering care to palliative care clients should be acknowledged and they should receive appropriate training and counselling.

- Funding barriers to the involvement of these workers in palliative care should be removed.
- The task of developing a trained work force of Aboriginal and Torres Strait Islander workers in palliative care may be more complex than attracting Aboriginal and Torres Strait Islander workers into HACC programs, however the HACC model may offer some valuable lessons.

Aboriginal Health Workers (AHWs) work for AMSs, community clinics, community health centres, and in some cases in hospitals as ALOs. Their roles vary from State to State.

In remote areas AHWs, together with clinic doctors and nurses, provide the only palliative care services available, and in some towns AHWs from the local AMS provide an informal (and untrained) palliative care role, often in their own time. Many AHWs spoke of the huge personal cost of this work as, especially in remote communities, the role is often akin to nursing their extended family and there is insufficient time to deal emotionally with the high number of deaths while other clients need to be cared for. Coordinators spoke of the need for additional resources to backfill positions so that AHWs could take the leave they needed.

AHW training should include a palliative care component, and funding is needed to employ and broker out trained workers as needed. In some regions it was suggested that an AHW with palliative care training could serve an entire sub-district or health region by being brokered out to various services as needed. In some regions it would be necessary to employ both male and female AHWs.

Where there is a significant Aboriginal and/or Torres Strait Islander population, trained Aboriginal and/or Torres Strait Islander palliative care workers are needed either as full-time palliative care workers or to undertake additional duties. How these positions are funded should not necessarily affect where they are based, which would depend on the local situation. It may be more appropriate to locate them in, or share them, with an Aboriginal and Torres Strait Islander service. A number of alternatives are suggested.

They could be regional workers, working throughout a health district with a number of service providers (mainstream and Indigenous), or they may be community based, or service provider based.

Two sorts of roles are needed: development and promotion roles to improve existing services; and hands-on or face to face roles dealing with cultural medical advocacy. Sample duty statements for these roles are given in Appendix 14.

In-patient facilities and domiciliary nursing services (both generalist and palliative care specialist units) should develop strategies to increase the numbers of Indigenous staff. Special programs to attract Aboriginal and Torres Strait Islander RNs should be developed, and cadetships or scholarships offered. Home-based services should employ ALOs to assist in development of their service and to liaise between mainstream nurses and Aboriginal and Torres Strait Islander clients.

There are very few Aboriginal and Torres Strait Islander nurses, doctors, psychologists and social workers involved in palliative care. Strategies to raise the awareness of these groups and to solicit their input into the development of culturally appropriate practice should be pursued through their professional associations eg CATSIN and AIDA.

j) Information (Chapter 7)

Most Aboriginal and Torres Strait Islander people and Aboriginal and Torres Strait Islander service providers (AMSs, HACCs, Community Aged Care [CACAP] and AHLOs) are not aware of what palliative care is or what services might be available. Information strategies are needed which address these issues.

‘Word of mouth’ strategies are the most effective in providing information and raising awareness in Aboriginal and Torres Strait Islander communities, and AHWs, ALOs and HACC workers will be the

key to the success of such strategies. Introduction of information about palliative care into undergraduate training programs for these workers will assist in the long term, and in the short term, other information strategies should be developed. Finding ways to encourage people to tell stories of good service, arranging information days and ‘yarning’ sessions were some of the strategies suggested to reach the community (see Chapter 7, Section 7.1).

Aboriginal and Torres Strait Islander community members who had experienced palliative care clearly identified the kinds of issues about which they wished they had received more information, and indicated that the earlier the information was available the better. As well as information about the range of services available (including Indigenous specific services), the clearest need was for the kind of information that has been provided in the *Palliative Caring at Home* booklets produced by the Palliative Care Associations of South Australian and Western Australia. These booklets could readily be revised to meet this need.

k) Training and education (Chapter 7)

There is an urgent need for the development and provision of palliative care training for Aboriginal health workers, for example, including a component in graduate courses and creation of post graduate certificate courses in palliative care, mental health and bereavement. There is also an urgent need for trained Indigenous psychologists and mental health workers to provide support or counselling in grief and loss.

Many GPs and specialist doctors are not aware of palliative care services and their benefits. Education and awareness programs for GPs encourage earlier referral to palliative care.

Community Controlled Health Organisations (AMSs) need education about palliative care and its benefits, and how they can get help from palliative care specialists for their clients. AMS doctors need to be reassured that palliative care does not have to mean that they must stop caring for the patient, and local arrangements for integrated delivery of service should be encouraged.

A specific module on Indigenous issues in palliative and bereavement care should be included in undergraduate training for all doctors and nurses, and professional development curricula for GPs, nurse practitioners and registered nurses should include palliative and bereavement care (for example, through continuing medical education programs for GPs, and the development of post-graduate courses for nursing graduates).

Cultural awareness programs may reduce the incidence of doctors making assumptions about clients’ wishes which deny their clients choices and may encourage doctors to seek appropriate cultural guidance.

Cultural awareness training is not uniformly available for palliative care service providers. Such training should be provided to all groups including generalist domiciliary nurses, hospital and hospice staff, and doctors.

It should be noted that generalist cultural awareness training of the kind that many health professionals receive is not adequate for the sort of cross cultural practice required of palliative care workers. Cultural training needs to deliver competence, not only ‘awareness’. Such training needs to provide opportunities for practitioners to review their own beliefs and values, develop skills and competence in cross cultural communication, and should encompass issues surrounding death and dying for Indigenous people – without implying that being sensitised to these issues confers cultural expertise. Cultural awareness

training or training to deliver competence in cross cultural practice, should equip practitioners to know when they should seek advice from cultural advocates and how to access such services. Local orientation will usually be required.

Cultural awareness training course design and delivery standards should be reviewed and standards developed so that courses deliver competency in cross cultural communications and practice.

Cultural awareness training must not be considered a substitute for the engagement of Aboriginal and Torres Strait Islander staff.

A great deal of informal counselling and bereavement support is provided by volunteers who are usually trained and coordinated by palliative care units. To date, volunteer programs have not attempted to recruit members from Indigenous communities. Some community members expressed interest in setting up similar groups, and some volunteer coordinators are keen to recruit Indigenous members. Both volunteers and their coordinators require cultural awareness training. Training currently provided to volunteers about palliative care could be immediately adapted for delivery to ALOs and AHWs as part of an information strategy (see above).

1) **Good practice (Chapter 8)**

Key elements in delivery of quality care include:

- early referral;
- cultural advocacy and brokerage;
- good communication and relationship development;
- clear coordination (i.e. everyone's role is clear);
- regular case management meetings, including cultural advocates;
- continuity of care; and
- flexibility and responsiveness which recognises individual needs.

A number of models are reported because they are said to work well in the communities where they operate. It is probable that none could be directly 'transported' elsewhere, however they may contain elements that would be appropriate in other places.

In the course of our investigation we discovered aspects of practice which we considered to be innovative and/or effective. Some highlights are listed below.

- Employment of Aboriginal and Torres Strait Islander staff.
- The staff of one palliative care service viewed themselves as coaches for the family, providing training and support so that they could look after a family member at home. They also provided specialist advice and coordinated other needed services (including access to residential facilities if required). This approach enabled family members to feel in control of care (see Chapter 8, Section 8.2.1).
- The provision of a comfortable and 'neutral' place that is readily accessible to family members and will not result in cultural avoidance problems after the death where the patient could pass away.

Some suggestions to achieve this (some of which have been put in place) included:

- development of care centres separate from hospitals where families could come for the terminal phase;
 - in remote communities, a room and family accommodation near the clinic that could be used during the terminal phase;
 - in regional urban areas, a public (or Aboriginal) housing authority could make a house available where families could stay for the duration of the palliation so they would not have to vacate their own home after the death.
- In-patient and residential palliative care facilities need to be better designed and managed to accommodate cultural practices. An extensive list of issues (see Chapter 5, Sections 5.4.3 and 5.4.4) and two best practice examples are provided (see Appendix 8 and Appendix 9).
 - In some other areas of health service provision, service providers are working to develop pathways of care (see Chapter 8, Section 8.4.2) which include checkpoints for cultural advocacy and cultural safety. Service providers argue that such pathways are needed in palliative care.
 - In a rural area in Victoria, mainstream and Indigenous service providers held a workshop and developed a set of regional network guidelines to assist them to communicate with each other and deliver more integrated services (see Appendix 12).
 - There are few examples of good practice in bereavement care. Some AMSs provide valuable practical assistance to families by assisting in the funeral arrangements and preparation of the ‘order of service’ and eulogies at the funeral service. These are highly appropriate bereavement care responses which could be enhanced by funding and equipping the health workers who undertake it with appropriate counselling skills. Other innovations and good practice in bereavement care are provided in Chapter 5, Section 5.5.6.

m) Standards (Chapter 8)

An objective of the National Palliative Care Strategy (2000) suggests that resources should be tied to good practice, however there is a danger that tying resource allocation to good practice will further disadvantage consumers who are not well served by existing services. Action needs to be taken to ensure that those services are improved rather than withdrawn because they do not meet standards.

The setting of standards in relation to these matters is not simple and needs to be approached with caution. Practice standards developed must give due weight to emotional, social, cultural and spiritual issues and must be carefully checked for their applicability to all Indigenous situations. In some cases the best palliative care for a person may involve their return to an environment which would not be regarded as meeting usual medical or personal care standards.

It may not in fact be practicable to set prescriptive standards for the delivery of culturally appropriate palliative care, however it should be possible to set standards for appropriate cross cultural communication and practice, such as: ensuring effective Indigenous input into policy; employment or participation of Aboriginal and/or Torres Strait Islander staff where possible; and effective communication between Indigenous and non-Indigenous service providers. Observance of these standards would need to be monitored by (culturally knowledgeable) third party interviews of consumers (see Section 8.5).

n) Funding and resources (Chapter 9)

Some significant structural issues were identified in our review of funding of palliative care for Aboriginal and Torres Strait Islander clients.

New initiatives in Indigenous funding focus on providing funding to fill gaps in the delivery of primary health care. Palliative care does not fit the definition of primary health care (being neither curative nor rehabilitative) even though it is often (and increasingly) delivered by primary health care providers. This, together with a general lack of awareness of palliative care, has probably resulted in palliative care not being identified as a priority issue in the first round of the regional planning upon which the Primary Health Care Access Program (PHCAP) formulas are based.

HACC funding guidelines now identify palliative care as a 'no growth' area. This is particularly significant to Aboriginal and Torres Strait Islander clients because HACC programs are amongst the few that successfully deliver services to Indigenous people at home, largely because of the employment of Indigenous HACC workers.

Most funding formulae for palliative care use cancer as a proxy. This means that the needs of HIV/AIDS, renal disease, cardio and respiratory disease palliative care clients may be overlooked. Aboriginal and Torres Strait Islander people are highly represented in these client groups which have been under-represented in palliative care numbers because traditionally these clients have not been referred to palliative care services.

Funding for Indigenous-specific initiatives appears to have been piecemeal to date. The New South Wales approach of adopting regional strategic plans which identify Aboriginal and Torres Strait Islander people as key target groups is commended, although these plans are framed in broad general terms and have not yet resulted in comprehensive or targeted funded initiatives. Further development and implementation of plans such as these will need to engage local Indigenous service providers and consumers in developing local priorities and solutions.

The multipurpose funding model used by one central Australian health service appears to be an effective way of ensuring that funds flow to identified local palliative care needs.

A number of service providers have suggested that funding packages similar to Community Aged Care Packages may allow them to purchase cultural advocacy services when required for Indigenous clients.

Enhanced Primary Care Items, (whereby Medicare payments may be claimed for multidisciplinary team care planning) should be marketed to palliative care and Indigenous health providers as a strategy to encourage the participation of Indigenous health providers into a more integrated (and better coordinated) service delivery for Indigenous clients.

In some circumstances, the funding arrangements for aged care facilities and nursing homes appeared to present barriers to clients receiving the best palliative care service in these facilities. Funding arrangements are needed that will allow aged care facilities and nursing homes to broker in palliative care services for symptom management advice, cultural support and additional nursing care when needed (see Chapter 9, Section 9.2.5).

Some key resource issues (see Section 9.3) were repeatedly raised with us by service providers. These included the following.

- The need for funding for Aboriginal and Torres Strait Islander staff. Such staff are needed in all regions where there is a substantial Aboriginal and/or Torres Strait Islander population. In all of Australia we identified only two Aboriginal staff employed directly by palliative care service providers. Even in areas where 50% of the clients are Aboriginal there are no Aboriginal staff.
- ACCHSs report that they are not funded for palliative care and have no specialist staff to undertake palliative care roles. Most ACCHSs operate only 9.00 – 5.00, five days per week, and if any palliative care services are provided, they are often undertaken by staff outside of normal working hours who are not paid for the additional work. Many would like to be able to provide staff to coordinate the care of clients with mainstream service providers and/or to provide Indigenous workers to accompany mainstream palliative care workers on home visits.
- There is a serious and widespread shortage of respite services, especially in places where Aboriginal and Torres Strait Islander people live. This makes it doubly difficult to care for family members at home effectively.
- Similarly, in many places where Indigenous people live access to allied health and ancillary services is a major issue. This ranges from access to speech pathologists and occupational therapists, to arranging home modifications. We repeatedly heard of waiting list periods which were longer than the life expectancy of the clients who needed the service.
- There were serious shortages of equipment in many areas and/or there was no funding for transport of equipment.
- In some areas, service providers acknowledged that funding restrictions prevented them admitting end stage renal cases as clients because if they were admitted while still on dialysis, they might live longer than the funding guidelines allowed.
- Lack of funds to allow for weekend visits by palliative care specialists was repeatedly raised as an issue.

In some areas there are no Indigenous specific aged care nursing home facilities; where there are aged care facilities, there are no (or too few) high care beds available.

In most States no fees are charged for palliative care services, however there is a widespread belief amongst Aboriginal and Torres Strait Islander people that these services do attract fees. Hidden costs of caring for family members at home, medication, home modification, equipment and power for heating and equipment, are significant however, and are costs that most can ill afford to pay.

o) Conclusions and recommendations (Chapter 10)

The goals and objectives of the National Indigenous Palliative Care Strategy were reviewed in the light of our findings. Suggested changes and additions are provided in Chapter 10, Section 10.2 and it is recommended that the Strategy be reviewed in line with these suggested changes.

i) Conducting demonstration projects and identifying resource shortfalls

It is clear that an infusion of funds is required in the short term to:

- develop the capacity of Aboriginal and Torres Strait Islanders to access and take part in delivery of palliative care services. Immediately, training for Aboriginal and Torres Strait Islander health workers, nurses, psychologists, social workers, doctors and allied health professionals is needed.
- develop services to provide culturally sensitive delivery of palliative care by improving the design and coordination of services, employing Aboriginal and Torres Strait Islander staff and improving the cultural competence of mainstream staff. Coordination must involve ACCHS and/or Area Health Boards.

It is estimated that five years' funding is required to develop pilot and demonstration projects which will set up the infrastructure, develop models of coordination and identify resource shortfalls so that the States and Territories could deliver needed services in a prioritised way.

This approach might be managed by the establishment of a committee of each of the State Partnership Forums (including the community controlled health sector) to develop State palliative care strategies for Aboriginal and Torres Strait Islander peoples. The intergovernmental forum on palliative care and the non-government sector should be engaged in this process.

ii) Some key targets

A number of key targets were identified, many of which are relevant to other culturally and linguistically diverse groups as well as to Indigenous peoples.

- Employment and training of Aboriginal and Torres Strait Islander staff to work in palliative care (see Chapters 6 and 7).
- Information strategies for Aboriginal and Torres Strait Islander communities and for decision makers working in Aboriginal and Torres Strait Islander health (discussed in Chapter 7).
- Education for GPs and AMS doctors to improve their understanding of palliative care and cultural issues surrounding death and dying. It is important that AMS doctors come to see palliative care as a special service which they can access for their clients and in which they can take a central role if desired. A targeted Continuing Medical Education (CME) package is suggested.
- Cultural and linguistic advocacy should be available to all clients who need it. All palliative care teams should have the capacity (service delivery design and resources) to engage cultural and linguistic advocates for their clients (both Indigenous and Culturally and Linguistically Diverse (CALD) clients). Such advocates need orientation in the objectives and methods of palliative care (especially respect for the individual's wishes) as well as cultural awareness training (in respect of the mainstream medical culture in which they will be working). Cultural advocates should also receive supported debriefing as part of their engagement.
- Improvement in the effectiveness, content and incidence of cultural awareness training (see Chapter 7).
- Improvement in hospital and hospice design and management for in-patient palliative care is needed in order to accommodate cultural requirements (see Chapter 5). These issues have wide applicability in the Australian context. Many of the needs identified are applicable to other culturally and linguistically diverse groups in situations relating to death in hospital.

iii) Research targets

- The way in which ‘bad news’ is delivered is critical to whether Indigenous people will access palliative care services. There is a need for State or regionally based research on how ‘bad news’ is usually delivered, how it should be done, the roles of family and cultural supporters, and links between the initial or subsequent advice of diagnosis and follow up actions such as referral to palliative care. Indigenous people need to be told about their condition in a way that is appropriate to their culture and that will support them in making informed choices about their future options. What is appropriate will vary from place to place.
- Contemporary Aboriginal and Torres Strait Islander modes of dealing with grief and loss, and the development of effective and accessible methodologies and programs in this area.
- Review of the incidence and effectiveness of cultural awareness training and developing competencies in cross cultural communication and service delivery.
- Development of models of palliative care pathways which include checkpoints for cultural advocacy and cultural safety.

p) Immediate actions that would help increase Indigenous people’s access to palliative care (Chapter 10)

Two key issues identified during the research were: the need for mainstream services to employ more Indigenous staff; and the lack of communication between the Aboriginal and Torres Strait Islander health sector and mainstream palliative care service providers. Each lacks awareness of the way the other operates and the services provided. Closing the communication gap so that the two sectors can work together to provide an integrated service would have a significant positive effect in increasing Indigenous people’s access to palliative care services.

The following actions could be undertaken immediately:

- Initiate a dialogue between mainstream and Indigenous service providers in your region or local area to find out what each does, what each has to offer and to work out how the gaps can be filled. The solutions should be developed in response to local circumstances and cultural needs. This action can be taken by individual service providers and/or Indigenous health services. It should be encouraged and supported by State governments and non-government associations.
- Development of an Indigenous palliative care network and ongoing Indigenous palliative care newsletter.
- Employ Indigenous people in local palliative care services (see model duty statement, Appendix 14).
- Schedule a planning workshop for the region for all relevant parties.

q) Conclusion

One of the immediate outcomes of this project has been that it has raised awareness of the issues involved in palliative care for Aboriginal and Torres Strait Islander clients, especially among both mainstream palliative care providers and Aboriginal and Torres Strait Islander health providers.

The need for Aboriginal and Torres Strait Islander people to be able to access culturally appropriate health services is a fundamental issue which service providers and policy makers must act upon. Mainstream service providers cannot assume that Aboriginal people will, or will not, be able to access palliative care services through an Indigenous health service and must make sure that their own services are appropriate and accessible, and/or that they are working in partnership with Indigenous organisations to deliver the best possible care.

References

(2000). *National Palliative Care Strategy: A National Framework for Palliative Care Service Development*, Commonwealth Department of Health and Aged Care.

Table of Key Findings appears on the following pages.

Table of key findings



	Finding	Ref	Page
Chapter 2 National survey of palliative care provision			
Availability of services	<p>Availability and structure of service delivery varies from region to region and State to State.</p> <p>Nationwide, only two palliative care services employ Aboriginal or Torres Strait Islander staff.</p> <p>ACCCHS/AMSs do not consider that they are palliative care service providers and are not linked to palliative care services.</p> <p>Some ACCCHS/AMSs do provide some palliative care services but lack training, expertise or support and do not offer after hours care.</p>	2.2	50
Chapter 3 Socio-economic and cultural contexts			
Socio-economic contexts	<p>Service providers and policy makers need awareness of socio-economic realities for Aboriginal and Torres Strait Islander peoples including poor housing, poverty, and poor underlying health (3.2) as well as the historical relationship between Indigenous peoples with health and welfare systems (3.2.7).</p> <p>The importance of self-determination and the role of community controlled health services must be acknowledged and recognised.</p> <p>Mainstream services need to engage with Aboriginal and Torres Strait Islander health service providers to provide an integrated service.</p> <p>Mainstream services need to modify service provision in consultation with local Indigenous communities to make services accessible and appropriate.</p>	3.4.1	82
Communication	<p>Barriers to communication include language and non-language barriers (see 3.2, especially 3.3.2).</p> <p>Cultural brokers and language interpreters are needed to provide quality palliative care to Aboriginal people and Torres Strait Islanders.</p>	3.4.2	82

	Finding	Ref	Page
Chapter 3 Socio-economic and cultural contexts <i>continued</i>			
Traditional issues	<p>In some regions, traditional issues are an important consideration for palliative care service providers (3.3).</p> <p>Traditional medicine is widely used in a many regions and access to traditional healers should be facilitated where it is requested (3.3.6).</p> <p>Protocols to ensure that end of life cultural practices are discovered and accommodated should be an integral part of palliative care service delivery (3.3.7).</p> <p>Service providers need to be aware of the complexity of traditional cultures and that some actions may have serious cultural repercussions (3.3.3 and 3.3.8).</p> <p>Whilst awareness and respect for Indigenous cultures is critical to providing a high quality of care, service providers should not expect to be able to 'learn Indigenous culture'. Cultural awareness training should aim to develop awareness, sensitivity and skills in cross cultural practice, without creating the impression that Indigenous culture can be 'taught'.</p> <p>Cultural interpreters should be engaged in some regions.</p> <p>Practices and protocols should be checked for cultural safety.</p>	3.4.3	82
Chapter 4 Access to palliative care services			
Referral issues	<p>The failure of GPs (both mainstream and employed by ACCHSs) to refer patients to palliative care services is a significant reason why few Aboriginal and/or Torres Strait Islander people do not access palliative care services (4.3).</p> <p>Aboriginal and Torres Strait Islander patients are often diagnosed very late in their illness and so if they are referred to palliative care, they are referred very late (4.3.5)</p>	4.6	103
Information and awareness	<p>There is a need for information strategies:</p> <ul style="list-style-type: none"> • to create awareness in Aboriginal and Torres Strait Islander communities about the nature and benefits of palliative care (4.4) • for ACCHS health professionals, including GPs • for mainstream service providers in cultural awareness and information about ACCHSs to build relationships and improve integration of services • 'word of mouth' strategies to enable Indigenous health and HACC workers to inform communities about palliative care, supported by appropriate printed information. 	4.6.1	103
Discharge planning (see also Chapter 5)	Better discharge planning (supported by cultural advocates) and the development of palliative care pathways which pinpoint key points requiring participation of cultural advocates is needed.	4.6.2	104

	Finding	Ref	Page
Chapter 4 Access to palliative care services <i>continued</i>			
Indigenous staff	Employment of trained Indigenous staff, or the brokering in of Aboriginal and Torres Strait Islander services is essential (see Chapters 6 and 7)	4.6.3	104
Supported referrals	Aboriginal and Torres Strait Islander people need culturally appropriate support at the time of referral to palliative care services (4.4) to ensure that they receive adequate information about the illness and the potential benefits of palliative care.	4.6.4	104
Relationship building	Relationships need to be developed between mainstream and Indigenous service providers Palliative care service providers need to develop relationships with Aboriginal and Torres Strait Islander communities and clients.	4.6.5	104
Breaking ‘bad news’	The way in which the patient and family are told about the illness is critical to Indigenous peoples’ access to palliative care services (4.6.6). GPs and specialists need training in cultural awareness and how to break ‘bad news’. Research is needed in this area – bodies representing Indigenous health professionals should be consulted on the design of the research.	4.6.6	104
Attitudes and assumptions (see also Chapter 5)	The attitudes and assumptions of service providers and health professionals play a critical role in whether Aboriginal and Torres Strait Islander people have access to or are offered palliative care services (4.3.1, 4.3.2 and 4.4.10; 5.1.1 and 5.9.1). Attitudes of Aboriginal and Torres Strait Islander peoples towards the mainstream health system, the presence of non-Indigenous strangers in their homes and a perceived lack of entitlement impact upon their ability and willingness to access palliative care services (4.4.9, 5.1.1 and 5.9.1) Attitudes and assumptions need to be challenged and changed through effective information and awareness strategies.	4.6.7	104
Eligibility	The range of serious and life-limiting conditions for which palliative care would be appropriate is much broader for Indigenous people than for the mainstream population (4.5). Though the incidence of cancer is similar to that of mainstream populations, there are much higher incidences of diabetes, respiratory and circulatory illnesses and renal disease amongst Aboriginal people and Torres Strait Islanders and they are more likely to present with a range of co-morbid conditions because of underlying poor health (4.5 and 9.2). Eligibility and funding rules need to be amended to include this broader range of conditions, in particular end stage renal disease (see 4.5.1).	4.6.8	104

Finding	Ref	Page
Chapter 5 Planning and delivery of care		
Expectations, attitudes and relationships	In general, Aboriginal and Torres Strait Islander people strongly dislike, distrust and fear hospitals and non-Indigenous strangers coming to their homes, in part due to historical factors. ACCHSs allow community control of health service delivery and need to become part of the palliative care network, or be able to access specialist palliative care services (5.1.1).	5.9.1 150
	<p>Service providers and their staff hold attitudes that affect their behaviour towards Indigenous clients and which are perceived as judgmental, yet appear to be unaware of a cultural divide (5.1.1).</p> <p>Service providers need to establish relationships with Aboriginal and Torres Strait Islander Health service providers, and ‘establish credentials’ and develop relationships with Aboriginal and Torres Strait Islander communities. Introduction by an Indigenous community member is essential, especially when time to develop a relationship is short (in palliative care context) and trust is critical.</p> <p>An immediate action that could (and needs to be) taken by Aboriginal and Torres Strait Islander and/or mainstream service providers is to establish a dialogue to find out what services each provides, what each has to offer and how gaps can be filled (see also this project’s Newsletter no.3 which outlines an approach to opening a dialogue and opportunities for cooperation).</p>	5.9.1 150
Discharge planning and assessment	<p>There is a need for development of care pathways for palliative care clients which ensure continuing involvement of the palliative care team, a cultural advocate (such as AHLO, AHW or Indigenous staff of the service provider) and family members (5.2.1).</p> <p>A question on Indigenous status should be asked on admission as a palliative care client.</p> <p>Appropriate Indigenous staff and/or cultural advocates need to be involved in assessment of palliative care clients (5.2.2).</p> <p>Assessment processes need to be sensitive to the circumstances of Indigenous clients – if possible, they should try to avoid a stream of different service providers, allow relationships to develop over several visits and deal sensitively with the dynamics of the household (eg in choosing the location for assessment, identifying decision-makers, etc)</p> <p>Service providers should ensure they have access to and funding for cultural specialists.</p>	5.9.2 151

Finding		Ref	Page
Chapter 5 Planning and delivery of care <i>continued</i>			
Place of death issues	It is well documented that, in general, Aboriginal people and Torres Strait Islanders wish to die in their own country or community (5.3.1).	5.9.3	151
<i>Early information, being prepared, choices</i>	<p>Clients and their families need information as early as possible about the nature of the illness and their options, so as to make informed choices (5.3.1-5.3.2).</p> <p>Late referrals reduce the client's capacity to make choices about end of life decisions.</p> <p>In remote areas sending patients to distant cities for treatment may result in them being unable to return to their own country or community to die (5.3.1). This should be considered carefully with the family as well as the client and options such as use of tele-medicine should be considered.</p>		
<i>Solutions for cultural dilemmas</i>	Cultural dilemmas (5.3.2) may arise in relation to the place of death, especially in regions where homes may need to be vacated after a death. (see 5.3.2 and 5.9.3 for possible solutions)		
<i>Advocacy</i>	Palliative care service providers and ACCHSs should advocate on behalf of clients to enable them to return to their home country or community whenever possible.		
Setting of care	Most Aboriginal and Torres Strait Islander clients and their families want the client to be cared for at home (5.4.1).	5.9.4	152
<i>Caring at home</i>	<p>There are barriers to provision of palliative care services at home (5.4.2) but service providers could make improvements in a number of ways, including: visits accompanied by Indigenous staff; taking time to establish relationships; competence in cross cultural communication and practice; providing good information; confidentiality (5.9.4).</p> <p>Availability of respite services is critical to enabling families to care for palliative care clients at home.</p> <p>Hospitals are seen as places of death rather than healing and many members of Indigenous communities remember relatively recent racist practices in local hospitals (5.4.3).</p>		
<i>Hospitals</i>	<p>Current design, visitor facilities and perceived attitudes of staff continue to present barriers (5.4.3).</p> <p>Staffing and care practices at hospitals should be reviewed and action taken (based on consultation with local Aboriginal and Torres Strait Islander communities), for example to increase the number of Aboriginal and Torres Strait Islander staff at all levels and ensure that staff receive cultural awareness training (5.4.3).</p>		
<i>Hospices</i>	In general, Aboriginal and Torres Strait Islander people whose family had used a hospice were very satisfied with the facilities and staff attitudes (5.4.4).		

	Finding	Ref	Page
Chapter 5 Planning and delivery of care <i>continued</i>			
Setting of care			
<i>Hospices</i>	Anecdotal evidence from two regions indicated that orientation visits for key community members and clients were very effective in informing and changing community attitudes (7.1.5).	5.9.4	153
<i>Nursing homes and aged care facilities</i>	<p>Aboriginal and Torres Strait Islander people are generally reluctant to place family members in such institutions, but Aboriginal and Torres Strait Islander people do reside in nursing home and aged care facilities, including mainstream facilities (5.4.5).</p> <p>The higher percentage of Aboriginal and Torres Strait Islander staff in Indigenous specific facilities provides a level of ‘cultural comfort’ for residents (5.4.5).</p> <p>More funding and more flexible funding is needed to ensure that aged care facilities and nursing homes can access palliative care services for their clients (5.9.4).</p> <p>In areas of high Aboriginal and/or Torres Strait Islander populations, designated Indigenous staff positions commensurate with the population the facility serves are needed (5.9.4).</p> <p>The capacity to backfill positions when staff are on bereavement leave is needed (5.9.4).</p> <p>Nursing homes and aged care facilities should ensure that all staff have undertaken cultural awareness training (5.9.4).</p> <p>Aboriginal and Torres Strait Islander residents of nursing homes / aged care facilities may wish to return to their home country to pass away. They should be supported to make this choice (even if there will be insufficient care facilities for them) (5.9.4).</p>		
<i>Medically supported hostels and palliative care for itinerant people</i>	<p>A need was identified for medically supported hostels for short term accommodation of Aboriginal and Torres Strait Islander palliative care clients visiting for remedial treatment (5.4.6).</p> <p>There is a need for strategies and funding arrangements for delivery of palliative care services to all people, including itinerant or ‘homeless’ people (5.4.7 and 5.9.4)</p>		
Counselling and bereavement care	<p>Aboriginal and Torres Strait Islander people have limited access to counselling and bereavement care services (5.5.1 and 5.5.2).</p> <p>Aboriginal and Torres Strait Islander communities carry an enormous burden of grief which goes largely unrecognised.</p> <p>The limited bereavement care and support available from service providers (such as HACC worker and AMS health workers) is often informal and unpaid, although it may be a very important (and practical) part of bereavement care (such as assisting with funeral arrangements).</p>	5.9.5	154

	Finding	Ref	Page
Continuity of care	<p>Most Aboriginal and Torres Strait Islander people would prefer to die at home, but in practice this may not happen or may not be possible.</p> <p>Flexible and responsive services are needed to ensure that continuity of care is maintained if the circumstances require a change of plan.</p> <p>Client tracking systems (especially in hospitals) that include cultural advocacy at key points and ensure that client's wishes are respected are needed.</p>	5.9.6	155
Pain management, medication and equipment	<p>There are many cultural misperceptions about how Aboriginal and Torres Strait Islander people experience and manage pain, which may lead to false assumptions by non-Indigenous health professionals. Apparent differences are due to cultural expression rather than physiological differences, as explained in recent publications (5.7.1).</p> <p>The cost of medication is a significant burden to many Aboriginal and Torres Strait Islander families. Many cannot afford the cost of medication and dispensing fees and may go without medication in order to pay for other family needs (5.7.2).</p> <p>Suitability of medication, and availability of medication on return to the home community of the client are important considerations (5.7.3).</p> <p>Many Aboriginal and Torres Strait Islander people are fearful about the use of morphine and there are apparently many misunderstandings about its use. There are safety and security issues associated with the use of morphine (5.7.5).</p>	5.9.7	155
Access to palliative care specialists <i>For health professionals</i>	<p>Access to specialist advice is especially important (and sometimes critical) in effective symptom management (5.8.1).</p> <p>Palliative care advice lines for GPs and nurses have been set up in many areas, but are not always well known and are not often used by GPs and AMS doctors (5.8.1).</p> <p>Palliative care service advice lines should be 'marketed' to GPs and AMS doctors.</p>	5.9.8	156
<i>Symptom management advice</i>	<p>Many palliative care nursing staff contact city hospitals for advice if no local advice line is available, and develop their own advice networks (5.8.1).</p> <p>Service providers should advocate on behalf of Aboriginal and Torres Strait Islander clients who do not have a telephone, either for telephone access or for alternative emergency procedures.</p> <p>Funding structures should allow for funding of telephones in these circumstances.</p>	5.9.8	156

	Finding	Ref	Page
Chapter 6 Workforce issues			
Aboriginal and Torres Strait Islander staff	<p>More trained Aboriginal and Torres Strait Islander staff are needed and should be employed in palliative care and support services, or their services bought in.</p> <p>More Indigenous staff would assist to develop relationships between mainstream service providers and Indigenous communities, and in development of culturally appropriate services.</p>	6.8.1	164
Aboriginal and Torres Strait Islander staff	<p>Training of Indigenous health workers in counselling, domiciliary and palliative care should be promoted, especially in remote areas.</p> <p>Additional Indigenous workers are needed in development and promotion roles and in hands on roles (see Appendix 14).</p> <p>There is a need to employ or broker in services of medically trained Indigenous cultural advocates (such AHWs, EN or RN) in hospitals, health services and palliative care services.</p>		
HACC workers	<p>HACC workers play an important role in delivering palliative care and should receive appropriate training and counselling.</p> <p>Funding barriers limiting or preventing involvement of HACC workers in palliative care should be removed.</p> <p>The HACC model may offer lessons for increasing the number of trained Indigenous workers in palliative care.</p>	6.8.2	165
Aboriginal Liaison Officers	<p>ALOs should be more actively involved in discharge planning and delivery of palliative care.</p> <p>ALO job descriptions, workloads, staff levels, qualifications and working conditions need to be reviewed.</p> <p>More ALO positions or increased working hours will be needed to increase their participation in palliative care support and liaison.</p> <p>ALOs should receive some medical training (because of the need for medical advocacy), and basic training in palliative care and about local palliative care services.</p>	6.8.3	165
Traditional healers	<p>Traditional healers play an important role in palliative care in some regions and funding should be available to facilitate access to them where necessary (such as fares, purchase of services).</p>	6.8.4	165

Finding	Ref	Page
Chapter 6 Workforce issues <i>continued</i>		
Language and cultural interpreters	<p>All palliative care services should have the capacity to engage interpreters where the family involved does not speak English.</p> <p>Funding is needed to broker in interpreter services or in some places to establish such services (eg there is a need in Perth to offer interpreters for several Aboriginal languages).</p> <p>Palliative care teams should have resources and capacity in to engage cultural advocates for clients.</p> <p>Cultural advocates need palliative care training, training in respect of the mainstream medical culture and supported debriefing as part of the engagement.</p>	6.8.5 166
Other Indigenous health professionals	<p>Strategies are needed to raise awareness of Aboriginal and Torres Strait Islander nurses, doctors, psychologists and social worker of palliative care.</p> <p>Indigenous health professionals should have input into the development and delivery of culturally appropriate practice, through participation of professional associations (such as CATSIN, AIDA).</p>	6.8.6 166
Chapter 7 Information, Education and Training		
General issues	<p>Trained Aboriginal and Torres Strait Islander staff are needed at State level (government and palliative care associations) and in services.</p> <p>Policy makers need greater awareness of palliative care issues and should ensure that Indigenous communities are engaged in advising on their particular needs.</p>	7.10 184
Information for communities	<p>‘Word of mouth’ strategies, involving participation of staff from AMSs, HACCS, CACP and AHLOs will be most effective.</p> <p>Communication strategies for communities and for decision makers working Aboriginal and Torres Strait Islander health are needed.</p>	7.10.1 184
Information for Indigenous clients	<p>More information about the nature of the illnesses and care options available, provided earlier, is needed by most clients.</p> <p>There may be barriers to communication for Indigenous clients and they have particular information needs (7.2).</p> <p>Meeting information needs requires different solutions in different settings, such as language interpreters, cultural and medical interpreters and support, printed information. (7.2)</p>	7.10.2 185

Finding		Ref	Page
Chapter 7 Information, Education and Training <i>continued</i>			
Information for Indigenous clients	There is a clear need for a booklet such as <i>Palliative Caring at Home</i> (produced by PCAs in SA and WA), revised for Indigenous audiences.	7.10.2	185
Information exchange between mainstream and Indigenous health providers	<p>There is little communication between mainstream and Indigenous health providers (4.3 and 7.3).</p> <p>Local planning workshops (including all Indigenous and mainstream service providers) are needed to initiate communication about what each service provides, establish relationships and working partnerships (5.4.2 and 7.3).</p> <p>Protocols are needed at local and regional levels.</p>	7.10.3	185
Education and training for Indigenous staff	<p>There is an urgent need for development and provision of formal training in palliative care, mental health and bereavement for Indigenous health workers (in undergraduate and post graduate courses).</p> <p>Indigenous health workers need training and awareness programs about palliative care and palliative care services in their State and region (Chapter 6 and 7.4)</p> <p>Indigenous health services and their staff need education about palliative care and its benefits and how to access palliative care specialists for their clients (4.3.2 and 7.6.2)</p> <p>There is a need for a post graduate certificate in palliative care for AHWs and for a component on grief and loss associated with palliative care in the Mental Health Certificate qualification (7.6.1-7.6.2)</p>	7.10.4	185
Education and training for other health professionals	<p>CME programs and post graduate certificate courses for nursing graduates in palliative care and bereavement are needed.</p> <p>Mainstream palliative care workers need cultural awareness training, tailored for the palliative care context, that will result in effective cross cultural practice and competence (7.7)</p> <p>Cross cultural education aimed at developing cross cultural partnerships between mainstream and Indigenous service providers are needed at local regional level.</p> <p>GPs and specialists need education and awareness about the potential benefits of palliative care for their clients and their role in delivery of palliative care (4.3.2 and 7.6.1).</p> <p>Organisations such as NACCHO, CATSIN, AIDA, together with OATSIH, should have an advisory role in development of appropriate education and training courses, and information and education programs.</p>	7.10.5	185
Education and training for other health professionals	<p>CME programs and post graduate certificate courses for nursing graduates in palliative care and bereavement are needed.</p> <p>Mainstream palliative care workers need cultural awareness training, tailored for the palliative care context, that will result in effective cross cultural practice and competence (7.7)</p> <p>Cross cultural education aimed at developing cross cultural partnerships between mainstream and Indigenous service providers are needed at local regional level.</p> <p>GPs and specialists need education and awareness about the potential benefits of palliative care for their clients and their role in delivery of palliative care (4.3.2 and 7.6.1).</p> <p>Organisations such as NACCHO, CATSIN, AIDA, together with OATSIH, should have an advisory role in development of appropriate education and training courses, and information and education programs.</p>	7.10.6	186

Finding	Ref	Page
Chapter 7 Information, Education and Training <i>continued</i>		
Cultural awareness training	<p>All palliative care workers and community nurses should have regular cultural awareness training and work experience opportunities to enable them to develop competence in cross cultural communication.</p> <p>Competencies in cross cultural communication and service delivery need to be developed and applied. Cultural awareness training needs to deliver more than 'awareness'.</p>	7.10.7 187
Volunteer programs and support groups	<p>Volunteer programs have not previously attempted to recruit volunteers within Aboriginal and Torres Strait Islander communities (7.9).</p> <p>There is interest in Aboriginal and Torres Strait Islander communities in participating in volunteer programs. Coordinators would need cultural awareness training and guidance from community advisers on recruitment and training approaches (7.9).</p>	7.10.8 187
Chapter 8 Some aspects of good practice		
Elements of good practice	<p>Key elements of good practice include: early referral, cultural advocacy, good communication, relationship development, clear coordination, regular case management meetings, continuity of care, flexibility and responsiveness (8.2.2)</p>	8.7.1 202
Good practice in Indigenous palliative care	<p>Employment of Aboriginal and Torres Strait Islander staff.</p> <p>Palliative care providers act as coaches, providing training and support to family (8.2.1).</p> <p>A comfortable and 'neutral' place for the person to pass away, which the family can readily access and which will not result in cultural avoidance problems after death.</p> <p>Good design and management of residential palliative care facilities that accommodate cultural practices (5.4.3 - 5.4.4., Appendices 8 and 9).</p> <p>Pathways of care that include checkpoints for cultural advocacy and cultural safety (8.4.2).</p> <p>Practical assistance to families is a valuable form of bereavement care (5.5).</p> <p>Workshops and planning sessions are needed to develop regional network guidelines that will assist in communication and delivery of integrated services (Appendix 12).</p>	8.7.1 202

	Finding	Ref	Page
Chapter 8 Some aspects of good practice <i>continued</i>			
Standards and monitoring	<p>The issue of palliative care standards should be approached with caution and practice standards must be checked for applicability to all Indigenous situations (8.5.1).</p> <p>Practice standards must give weight to emotional, social, cultural and spiritual issues (8.5.1).</p> <p>Rather than prescriptive standards for delivery of culturally appropriate care, standards should be established for effective cross cultural communication and practice, such as ensuring Indigenous input into policy development, ensuring employment and participation of Indigenous staff and cultural advocates.</p> <p>There is a need for systems for monitoring and review of effectiveness and quality of delivery of care to Aboriginal and Torres Strait Islander clients (8.5.2).</p> <p>Where standards are not met, services should be improved rather than withdrawn because they do not meet standards.</p>	8.7.2	203
Chapter 9 Resources, fees and funding			
Structural funding issues	<p>Palliative care does not fit into the definition of primary health care but is increasingly delivered by primary health care providers (9.2.2).</p> <p>HACC services often provide palliative care services, but HACC funding guidelines now identify palliative care as a 'no growth' area (9.2.3).</p> <p>The use of 'cancer as proxy' funding formulae appears inappropriate to the needs of Aboriginal and Torres Strait Islander palliative care clients (4.5 and 9.2).</p> <p>Multipurpose funding for rural and remote communities may be effective in ensuring funding for palliative care services, but the scheme is currently used by only community (9.2.6).</p> <p>Packages similar to CACP may enable service providers to purchase cultural advocacy services for palliative care clients.</p> <p>Enhanced Primary Care items (Care Planning and Case Conferencing) could support more integrated and better coordinated service delivery for Indigenous clients and should be 'marketed' to palliative care and Indigenous health providers.</p> <p>Funding arrangements may present barriers to clients receiving quality palliative care in aged care facilities and nursing homes. These facilities require funding arrangements that enable them to broker in palliative care services, additional nursing care and cultural support for Indigenous clients (9.2.5).</p>	9.5.1	215

	Finding	Ref	Page
Chapter 9 Resources, fees and funding <i>continued</i>			
Resource issues	<p>Funding is needed for employment of more Aboriginal and Torres Strait Islander staff (9.3).</p> <p>ACCHSs are not funded to provide palliative care, do not employ specialist staff and usually do not provide after hours service.</p> <p>There is a widespread, serious shortage of respite care services, especially in regions of high Aboriginal and Torres Strait Islander population.</p> <p>Funds available for personal care and home help services are inadequate. These services are not funded to provide palliative care and sometimes ‘close the books’ to palliative care clients.</p> <p>Funds are needed to address serious equipment shortages and cover costs of transporting equipment.</p> <p>There is no funding for Indigenous liaison positions.</p> <p>Funding is not available to cover after hours visits by palliative care specialists.</p>	9.5.2	215
<i>Costs related to cultural needs</i>	<p>The cost of temporary housing, transport to return clients to home communities, traditional healers, transport of deceased to home country, language and cultural interpreters, and support to families in preparing funerals should be recognised as legitimate costs of provision of palliative care.</p>		
<i>Indigenous specific aged care facilities</i>	<p>In some regions there are no Indigenous-specific nursing homes or aged care facilities; where they exist there are too few high care beds (9.3.8).</p>		
Flexible funding	<p>Funding needs to be flexible so that palliative care ‘packages’ can be purchased when needed – for example, additional resources that allow a palliative care patient to remain in an aged care facility, or in a remote community in their home country (9.2.7).</p>	9.5.3	216
Fees	<p>A widespread belief amongst Aboriginal and Torres Strait Islander peoples that fees will be charged for palliative care services discourages them from accessing the services. (9.4).</p> <p>In general, fees are not charged or are waived for clients who cannot afford them, however Aboriginal and Torres Strait Islander clients may be reluctant or unable to seek a waiver. Most Indigenous families do not have the financial resources to pay contributions for home care services, equipment or cost of medication. Few have private health cover.</p> <p>The absence of fees (and fee waiver schemes) needs to be better publicised, and funding support schemes should be developed to assist people in hardship who cannot afford the ‘hidden costs’ of caring for someone at home.</p> <p>Fees charged by home nursing services should be reimbursable through Medicare.</p>	9.5.4	216

Finding		Ref	Page
Chapter 10 Summary of findings and conclusions			
Issues for palliative care policy makers and service providers	<p>Policy makers and/or palliative care service providers could undertake an advocacy role for Aboriginal and Torres Strait Islander clients on issues such as:</p> <ul style="list-style-type: none"> • Housing (to enable relocation during palliation, and for family after the death) in regions where there are powerful cultural traditions surrounding the place of death (5.3 and 5.9.3). • Ensuring that palliative care and Indigenous health providers and Indigenous liaison staff are involved in hospital discharge planning (4.3.6 and 5.2.1). • Development of ‘tagging’ systems in hospital that palliative care clients are identified on admission to emergency wards (5.6 and 5.9.3). • Changes in hospital practices in areas such as attitudes and expectations, appropriate spaces for visitors, allowing time for families to be with deceased and design of facilities to meet cultural needs of Indigenous clients (5.3.3 - 5.3.4). • Development of culturally appropriate grief and loss counselling strategies and services (5.5). 	10.1.5	218
Lack of resources	There are insufficient resources for the provision of palliative care services and there are some major gaps in the services that are provided (Chapter 9)	10.1.7	219
Lack of palliative care training	<p>There exists an urgent need for development and provision of appropriate training, inclusion of palliative care in undergraduate courses and development of post-graduate courses (6.6).</p> <p>There is a need for medically trained Indigenous advocates (6.6).</p> <p>Indigenous staff working in palliative care need adequate supervision and debriefing (5.5.7).</p>	10.1.8	219
What community members want	<p>Early information and support (5.5.7).</p> <p>More information about the course of the illness and what to expect, including at final stage (7.2).</p> <p>More information about services (7.10).</p> <p>Respite care (5.4.2).</p>	10.1.9	220
Implications for the National Strategy	The research findings indicate several areas where the NPCCS could be strengthened to take into account the special needs of Aboriginal and Torres Strait Islander peoples. The following summarises recommendations detailed in Chapter 10, Section 10.2.	10.2.1	220

	Finding	Ref	Page
Chapter 10 Summary of findings and conclusions <i>continued</i>			
Implications for the National Strategy	<p data-bbox="555 495 959 528">Goal 1: Awareness and understanding</p> <p data-bbox="555 544 1177 667">The research revealed a great need to increase awareness of palliative care and what it can offer, for professional training and for strategies to ensure that Aboriginal and Torres Strait Islander people can access the services they need.</p> <ul data-bbox="555 685 1201 1122" style="list-style-type: none"> <li data-bbox="555 685 1139 745">• Good word of mouth strategies are needed to inform Indigenous communities. <li data-bbox="555 759 1182 846">• Training and education is needed for health workers and health professionals working in the Aboriginal and Torres Strait Islander medical sector. <li data-bbox="555 862 1201 949">• For mainstream services, strategies aimed at increased awareness of the Indigenous peoples cultural needs and recruitment of Indigenous staff and volunteers, are needed. <li data-bbox="555 965 1201 1122">• Increased awareness at State and Australian Government level to ensure that Indigenous peoples' needs are taken into account and that Aboriginal and Torres Strait Islander health organisations are actively engaged in developing policy. 	10.2.1	220
	<p data-bbox="555 1155 914 1189">Goal 2: Quality and effectiveness</p> <p data-bbox="555 1205 1193 1328">While it is important to set high quality standards in delivery of care, it is also important to ensure that they are suitable for all situations, particularly in delivering care to Aboriginal and Torres Strait Islander clients.</p> <ul data-bbox="555 1346 1185 1845" style="list-style-type: none"> <li data-bbox="555 1346 1134 1406">• Setting of care standards should be approached with caution. <li data-bbox="555 1420 1134 1480">• Standards should be established for appropriate cross cultural communication and good cultural practice. <li data-bbox="555 1494 1185 1581">• Palliative care services should be encouraged to develop good practice locally, in partnership with local Aboriginal and Torres Strait Islander health services. <li data-bbox="555 1594 1185 1682">• Aboriginal and Torres Strait Islander patients may have special resource needs which should be recognised as part of the cost of providing good palliative care <li data-bbox="555 1695 1166 1845">• Care pathways should aim to ensure that Indigenous clients are referred early and have good cultural support throughout their care; palliative care services need to develop systems to check the quality of their services to Indigenous clients. 	10.2.2	222

	Finding	Ref	Page
Chapter 10 Summary of findings and conclusions <i>continued</i>			
Implications for the National Strategy	<p>Goal 3: Partnerships in care</p> <p>Strong relationships between Indigenous communities and mainstream service providers in palliative care need to be developed and fostered through:</p> <ul style="list-style-type: none"> • Local planning workshops, • Strong local and regional protocols, • Training and employment of Aboriginal and Torres Strait Islander staff in mainstream palliative care services. • Employment of trained Indigenous staff in policy development 	10.2.3	224
10.3 Conclusions: immediate and medium term actions and targets			
Demonstration projects and resource shortfalls	<p>An infusion of funds is required in the short term for:</p> <ul style="list-style-type: none"> • Training for Aboriginal and Torres Strait Islander health workers, nurses, psychologists, social workers, doctors and allied health professionals to develop the capacity of Aboriginal and Torres Strait islander communities to access and take part in delivery of services. • Improving design and coordination of services, employment of Aboriginal and Torres Strait Islander staff and improving cultural competence of mainstream staff. • Pilot and demonstration projects, some at State or regional level and some at local level, giving high priority to training, planning and coordination. <p>Five years' funding is required to develop pilot and demonstration projects to establish infrastructure to enable States and Territories to prioritise and deliver needed services.</p> <p>Projects could be managed by a committee of each of the State or Territory Partnership Forums which would develop palliative care strategies in consultation with the community controlled health sector and non-government bodies such as State Palliative Care Associations and Cancer Councils.</p>	10.3.1	225
Key targets	<p>Employment and training of Aboriginal and Torres Strait Islander staff to work in palliative care (Chapters 6 and 7).</p> <p>Information strategies (Chapter 7).</p> <p>GP and AMS (ACCHS) doctor education (Chapter 7).</p> <p>Cultural and linguistic advocacy (3.2.8 and 3.3.2).</p> <p>Cultural awareness training (Chapter 7).</p> <p>Hospital and hospice design and management</p>	10.3.2	226

Finding	Ref	Page
10.3 Conclusions: immediate and medium term actions and targets <i>continued</i>		
Research targets	<p>Four key areas for research are identified:</p> <ul style="list-style-type: none"> • The way in which ‘bad news’ is delivered and the roles of family and cultural supporters, as this stage and subsequent follow up are critical to Indigenous access to palliative care services (Chapter 4). • Contemporary Aboriginal and Torres Strait Islander modes of dealing with grief and loss and development of effective, accessible methodologies and programs (5.5). • Review of the effectiveness of cultural awareness training and development of competencies in cross cultural communication and service delivery (Chapter 7). • Development of model palliative care pathways which include checkpoints for cultural advocacy and cultural safety (5.6 and 5.9.2). 	10.3.2 226
Immediate actions to increase Indigenous access to palliative care	<p>Dialogue should be initiated between mainstream and Indigenous service providers at local/regional level to establish what each does, what each offers and how gaps can be filled. Solutions should be developed in response to local circumstances and cultural needs. The process should be encouraged and supported by State governments and non-government associations.</p> <p>Development of an Indigenous Palliative Care Network and ongoing Indigenous palliative care newsletter.</p> <p>Employ Indigenous people in local palliative care services (model duty statements are provided in Appendix 14).</p> <p>Schedule a planning workshop at regional level for all relevant parties.</p>	10.3.3 227

Chapter 1

Background and methodology



1.1 The brief

The Study was commissioned by the Australian Government Department of Health and Ageing, Mental Health Branch. The main objectives of the project as set out in the tender project description were to identify:

- (a) Existing activities in palliative care for Aboriginal and Torres Strait Islander peoples at the Australian Government, State/Territory and community levels. This should include mainstream activities which incorporate Indigenous components as well as Indigenous specific activities;
- (b) Areas that could be enhanced or developed under the National Palliative Care Strategy (2000) at the Australian Government, State/Territory and community levels;
- (c) The needs of Aboriginal and Torres Strait Islander peoples for palliative care, taking into account the diversity of Aboriginal and Torres Strait Islander communities and the different needs for rural, remote and metropolitan settings; and
- (d) Spiritual and cultural practices that relate to death and examine the extent to which these are being implemented in a culturally sensitive way, taking into account the diversity of settings and cultural beliefs.

The study was conducted in four main parts:

- In **Stages 1-3** (March-April 2002) a literature review (looking at previous research and other documented activities) and scoping study were conducted. State and regional agencies, service providers and community organisations were contacted by telephone to identify palliative care services in their regions.
- **Stages 4-5** (May-July 2002) focused on developing field methodology (the steps to be followed when visiting and talking with communities and organisations) and building partnerships with communities which consultants were to visit later.
- During **Stages 6-7** (August-November 2002) field work was conducted in rural and remote areas and some towns and cities. A question sheet was posted to community organisations in selected communities that could not be visited.
- **Stages 8-9** are the reporting phases. The final report consists of a detailed report for the Australian Government Department of Health and Ageing (this report) and a short report (newsletters 3 and 4) which will be circulated to all communities and organisations that have participated in the study.

1.2 The steering committee

The steering committee for this project included representatives from:

- the Congress of Aboriginal and Torres Strait Islander Nurses;
- the Aboriginal and Torres Strait Islander Research Agenda Working Group of the National Health and Medical Research Council;
- the Intergovernmental Forum on Palliative Care (State/Territory representatives); and
- the National Aboriginal Community Controlled Health Organisation (NACCHO).

The steering committee reviewed interim reports, methodology proposals and newsletter texts and provided invaluable support, advice and guidance.

1.3 The scoping study

Letters outlining the project and inviting input were written to:

- all the State and Territory Associations of Aboriginal Community Controlled Health Services (ACCHS);
- all State Health Departments;
- all ATSIC Regional Councillors;
- regional Aboriginal organisations (eg Northern Land Council, NPY Women's Council, Apunipima in Far North Queensland, and some regional Indigenous health providers like Nganampa Health Council and Ngaanyatjarra Health Service Aboriginal Corporation); and
- a range of stakeholders including Nurses Associations, Carers Associations, major Church organisations, Royal Flying Doctor Service, Division of General Practice, Rural Doctors' Association etc.

The scoping study methodology followed that set out in the tender and took place by telephone. Sets of scoping questions were developed for telephone interviews, including separate sets of questions for State or national level informants, regional level informants, and service providers. These questions were also posted on the project web site at <http://member.telapacific.com.au/ksa>.

The intention was to develop a tiered information framework, first to understand the structure of palliative care for each State and Territory, then to discover what Indigenous-specific services exist and, finally, to undertake interviews with some of these services providers.

In each State and Territory telephone calls were made to officers of:

- Office of Aboriginal and Torres Strait Islander Health (OATSIH)
- State Health palliative care representatives
- State Health Aboriginal and/or Torres State Islander Units
- State Government Aged Care Sections or Departments
- Palliative Care Australia (PCA) State divisions
- major regional Aboriginal and Torres Strait Islander organisations
- some Aboriginal and Torres Strait Islander service providers
- some non-Indigenous Service Providers

Representatives of the Aboriginal and Torres Strait Islander HACC Reference Group and various Australian Government Health and Ageing funding program representatives were also contacted by phone.

In addition to the methodology agreed to in the brief, we developed a questionnaire which was sent to all mainstream palliative care service providers listed in the Palliative Care Australia mailing list. The main purpose of this questionnaire was to find out about the levels of access by Indigenous clients to mainstream palliative care services and to gain information about perceived needs and issues from those with Indigenous clients. A copy of this questionnaire is at Appendix 1.

1.4 Scoping study responses

Many of the people we spoke with at this stage of the project were public servants, however the information about service models and the comments on issues and needs has come primarily from service providers working on the ground. About half of these informants were Aboriginal and/or Torres Strait Islander people.

Most State agencies were very helpful in providing information and advice. Few provided (or were able to provide) the lists of palliative care providers we sought. NSW Health preferred to circulate a copy of our questions to their regional officers, rather than put us in contact with them.

Some agencies were better than others at responding to telephone calls. At least 98% of our calls were answered or returned positively. We did not receive a response from any State or Territory Associations of ACCHS during this phase of the study. From the 76 letters we sent to stakeholders, ATSIC Regional Councils and regional community organisations, we had eight responses, six of which provided information and two of which indicated no involvement in palliative care. The letters we sent proved a useful introduction to the project for telephone respondents. When we telephoned many of the organisations we had written to, having been referred to them from State level enquiries, phone responses were generally positive and helpful.

Responses to the mainstream service questionnaire were as follows.

NUMBER OF RESPONSES BY NUMBER OF INDIGENOUS CLIENTS:							
Numbers of Indigenous clients	0	1	2-5	5-10	10-20	20+	Total Responses
Number of responses	46	12	19	3	2	1	83 i.e. 29.3 %

A response rate of approximately 30% is very high for this sort of survey.

While the methodology is dependant upon the knowledge of the people we spoke with, we are confident that this initial scoping identified the major activities in Indigenous palliative care. A level of confidence is gained from the fact that we were repeatedly told the same things and referred to the same organisations as providers of palliative care to Aboriginal and Torres Strait Islander clients. Data from the mainstream questionnaire is summarised in Appendix 2 and discussed in Chapter 4.

NEWSLETTERS - RESPONSES BY STATE:

Newsletter	NSW	ACT	VIC	TAS	SA	WA	NT	QLD
No.1	9	1	4	1	1	4	6	9
No.2	3	-	1	-	1	6	1	8

The findings of the preliminary scoping study were reported in an interim report at the end of Stage 2 and have been incorporated into this report.

1.5 Previous research and relevant literature

The literature search involved searches of available databases and review of bibliographies of studies that had already been located. Further references were also gathered during the scoping study and fieldwork.

The database lists of major universities were reviewed and databases to be searched were selected. Those selected fell into three broad categories:

- collections centred on Aboriginal and Torres Strait Islander and multicultural issues;
- collections of medical, allied health and sociological issues; and
- collections of anthropological or ethnological research.

The following databases were searched:

- ATSIROM
- ATSIC Library catalogue
- ATSIhealth
- IndigiNet
- HealthInfonet
- Menzies School of Health Research
- AMI (Australian Medical Index)
- AMED (Allied and contemporary medicine)
- AUSTHealth
- CINAHL (Cumulative Index to Nursing and Allied Health Literature)
- APAIS (Australian Public Affairs Information Service)
- APAIS-Health
- Health and Society Database
- RURAL (Rural and remote health database)
- AUSTROM:FAMILY
- AIATSIS catalogue
- RCIADIC (Royal Commission into Aboriginal Deaths in Custody)
- The Cochrane Library

The search results were reviewed, an annotated bibliography developed, and specific items were selected for further consideration according to their relevance for this study. The 'Indigenous Palliative Care Bibliography' is attached at Appendix 4 together with a list of international references collated from data bases and a 'Training Resource Bibliography'.

An 'Anthropological Bibliography' containing items from a range of data bases (primarily the AIATSIS database) was assembled. Many of the references deal with traditional mortuary practices and do not inform the current study. While some of the ethnographic data is relevant to current beliefs and practices, it is unlikely to be of use to palliative care service providers or policy makers. Selected items that may be of interest are listed as Anthropological Library in Appendix 4.

Summaries of the most significant reports of field research to date (Collis-McAnespie, Dunn et al. 1997) (Mobbs 1995) (Wagstaff 1997) (Williamson 1996), several significant articles; (Prior 1999), (Prior 2001) (Fried 1999) and (Fried 2000), and a recent theses (Fried 2000) highlighting the key points raised, are provided in Appendix 5.

1.6 The field work

1.6.1 Methodology development

The three types of field work planned involved:

- regional needs analysis;
- good practice studies; and
- facilitation of protocol development (one location only, in Victoria)

The methodology was developed during May and June and was circulated to the steering committee for comment. The methodology paper which was submitted to the Aboriginal Health and Medical Research Council (AH&MRC) NSW is attached at Appendix 6.

1.6.2 Field work locations

The field locations were selected in locations and regions where:

- there is a relatively high Aboriginal and/or Torres Strait Islander population, but little is known about palliative care service delivery to Aboriginal and Torres Strait Islander clients (regional needs analysis);
- we had received reports of good practice.

Consideration was given to where previous studies had been conducted and to where other research projects were underway, so as not to duplicate work unnecessarily. It was seen as important to build upon, rather than replicate, previous research, done in specific regions.

The election of location was endorsed by the steering committee after discussion. The field work was conducted in the following locations:

Northern Territory	Victoria
Darwin	Shepparton-Mooroopna
Alice Springs	
Tennant Creek	New South Wales
Tiwi Islands ¹	Nowra
	Kempsey
Central Australia	Western Sydney
One community/ health service district	
	Queensland
Western Australia	Mt Isa
Kimberley	Cairns and District
Kalgoorlie	Rockhampton
Perth	Torres Strait
	Brisbane
South Australia	
Adelaide and a rural/regional area	

In the case of organisations or locations which we would have liked to include in our field work but which we could not visit (due to logistics or budget), question sheets which mirrored the information being collected (and headed by an informed consent form) were forwarded for completion. (see below Needs Survey questionnaires). The information from these responses has been incorporated into this report.

1.6.3 Ethical approvals

We wrote to each State ACCHS umbrella body about ethics procedures. The response in each State was as follows.

Western Australia

In Western Australia we were referred to the Western Australian Aboriginal Health Information and Ethics Committee (WAAHIEC). Our paper was received the day before the next scheduled meeting and was not considered. WAAHIEC advised that a submission for ethics approval needed to be provided in their own format and that the next meeting was scheduled for mid-late September. This meeting was delayed due to a bereavement but approval was granted at the re-scheduled meeting on 4 October. As a result, our field work in Western Australia was delayed by several weeks and resulted in some changes to field locations.

¹ At the request of the Tiwi Health Board we developed a special set of questions for Tiwi health workers which was administered in the Islands by Mr Jeremy Smith of the Board.

South Australia

The Aboriginal Health Research Ethics Committee (AHREC) of South Australia meeting on 11 July gave conditional endorsement, pending information about sample size and timing. This was supplied and approval was granted.

Queensland

Mr Mick Adams, CEO of the Queensland Aboriginal and Islander Health Forum (QAIHF) advised us that they were satisfied with our approach to the proposed fieldwork and invited us to address their annual general meeting in Mackay in August. Luana Johnston addressed the meeting and field work proceeded.

Northern Territory

The Aboriginal Medical Service Alliance of the Northern Territory (AMSANT) considered the matter at their annual general meeting and advised that since we had ethics approval from another state (South Australia) they did not require any additional submissions and were happy for us to proceed.

Victoria

We were advised that the Victorian Aboriginal Community Controlled Health Organisation (VACCHO) ethics committee was not currently operational and in any case the nature of the work in Victoria was similar to that in the other states. We therefore wrote to VACCHO to inform them about the project but not to ask for approval.

New South Wales

The methodology proposal was submitted to the AH&MRC (NSW) on 12 June for their meeting on 19 June. On 6 August we received advice to say that they had referred the matter to NACCHO. No response was received from them until 8 January 2003, by which time the field work had concluded. The field approach in New South Wales was therefore modified (see below). The committee raised a number of issues which have been responded to.

1.6.4 Methodological issues encountered in the field

The interview guidelines set out in Appendix 6 were used throughout as a guide to interview, with the language being modified where necessary. The questions were usually read as printed and then restated in a way more appropriate to the local situation and language. Group discussions took between 1.5 - 2 hours. One on one interviews usually lasted about one hour.

The information sheets and informed consent forms used were the same for each State and Territory and varied only in the provision of contacts for local (State) ethical approval bodies and in recording the status of the relevant request for ethical approval. In New South Wales the information was changed to indicate that the AH&MRC was still considering our proposal.

The delay in obtaining ethical approval in New South Wales meant that the field work could not be undertaken by Jennifer Beale and Jack Gibson. It was instead undertaken by Kate Sullivan and Jennifer Beale in one location and by Kate Sullivan and Kerry Welsh in two other locations.

The time required to arrange meetings and liaise by phone, fax and email prior to field work far exceeded that allowed for. In most cases it took far longer to arrange visits and meetings than it did to carry them out, however the careful planning meant that the field visits went smoothly and that solid relationships were developed prior to visits.

A significant aspect of the field work was the importance of the local contact person who undertook the recruiting of community members. This person was usually a representative of a local AMS² or HACC program. The role of this person was extremely important.³ Details of the recruitment process they were asked to use is provided in Appendix 6. Considerable time was spent in telephone communications with the local contact prior to visits and in face to face meetings before the group discussion. The role of these people varied but they usually (especially on the occasions where an Indigenous team member was not present) sat in on the interview, provided introductions and assisted in translation of questions to suit local circumstances or generally assisted with communication issues. Their contribution to the project was substantial.

Participation issues

- It is noted that the mainstream palliative care responses contained only a very few from major hospitals, many of which provide palliative care services.
- In many centres it was difficult to identify many Aboriginal and/or Torres Strait Islander community members who had had experience of palliative care because of the low numbers of Aboriginal and/or Torres Strait Islander people accessing these services. These people were usually identified for us by the local AMS or other Aboriginal Health service provider. We are confident that in any given centre we spoke with most of the people who fitted our criteria, however, as we were consistently referred to the same people by both mainstream and Aboriginal and Torres Strait Islander service providers.
- We found that speaking with Aboriginal (and Torres Strait Islander) Health Workers (who are also community members) was very fruitful as they were able to speak about how community members managed when a family member had a life-limiting illness (even though they may not have accessed palliative care services) and they were also able to make informed comment about access to services.
- The number of people interviewed during the field work is set out in the table below. Every effort was made to engage with Aboriginal and Torres Strait Islander community members and health workers.
- The majority of people we spoke with were women. This is to be expected as the main carer role in many communities falls to women. Views expressed by the men we spoke with were not substantially different from those expressed by women.
- While we specifically asked *not* to speak with people who were more recently bereaved than six months, we did speak with some (about five people) who were more recently bereaved because these people specifically wanted to speak with us. In each case these peoples' willingness to take part was double and triple checked and they were reassured that they could change their minds at any time. These people signed a modified consent form. Where it seemed appropriate, the local community contact who had recruited participants (see above) was asked to (or themselves initiated a) check on the person the next day to see that they were all right. Feedback from these and indeed all interviews was that the participants were very pleased to have had the opportunity to speak with us and with others in the small groups about their experiences.
- As we had not received a response from the Ethics Committee in New South Wales by the end of our planned field season and given the time constraints of the project, we modified our field strategy in New South Wales after consultation with the funding body. We were not able to recruit community members to interview through the AMS (i.e. patient records) so we concentrated on service provider

² We use the term AMS to refer to the local Aboriginal Community Controlled Health Service (ACCHS) because it is generally the term which our informants use to describe the local ACCHS.

³ Some times the work was done in their own time and was reimbursed and sometimes in the time of their employer. All organisations were made written offers of reimbursement for time and venue use.

interviews. We spoke with mainstream service providers and AMS doctors and health workers in all three areas visited. In all cases the New South Wales AMSs were informed that we did not have ethical approval. We spoke with community members recruited in two of the three locations using other contacts. Informed consent, including disclosure that we had not received a response from the ethics committee, was gained in all cases.

In (NSW Rural area 1) we met with a group of nine elders and the AMS arranged for us to speak with a group of five health workers who had a community perspective. In western Sydney, we used local contacts to locate people with experience of palliative care. In (NSW Rural area 2) we did not interview any community members but spoke with health workers and AMS doctors and health workers.

FIELD WORK INTERVIEWS BY LOCATION											
State	Indigenous							Non Indigenous			
	Nurse/ Doctor	HW	ALO	Comm. Member	Manager	Worker HACC	Other	Nurse	Doctor	Manager	Other
ACT											
NSW		7	6	14	6	5	0	8	5	2	2
NT	1	14	2	9	3	3	0	2	5	8	3
Cent A	0	0	0	18	0	2	0	5	2	2	1
SA	0	6	0	28	3	3	1	5	5	3	1
QLD	8	5	8	36	10	1	0	10	15	14	7
TAS	0	0	0	0	0	0	0	0	0	0	0
VIC	1	1	1	5	1	1	0	5	1	4	0
WA	4	7	5	18	4	7	3	9	6	10	5
Totals	14	40	22	128	27	22	4	44	39	43	19
							257				145

1.7 Needs Survey Questionnaires

The intent of the stage 6 questionnaire was to make contact with organisations or communities that we could not include in our field work but which we thought would have a view on future needs and issues related to our study.

Originally we had intended to send 600 questionnaires at this stage, however during the scoping stage of the study (Stages 2 and 3), we sent a detailed questionnaire (which also canvassed needs and issues) to all mainstream palliative care service providers as identified to us by Palliative Care Australia and State government agencies (N=283). 30 % of these service providers responded. Most had no Indigenous clients and of those that did most had only one or two clients. It is highly likely that the 70% who did not respond had no Indigenous clients. The results of the mainstream questionnaire were used to plan the fieldwork locations and methodology.

The 'Needs' questionnaire (covering some of the same ground as the Stage 3 'Mainstream' questionnaire) was directed to organisations which we felt would have an Aboriginal and/or Torres Strait Islander or a practical perspective on future issues and needs.

Stage 3 questionnaires were sent to	283
Stage 6 questionnaires were sent out to:	
• Community Controlled Health Organisations	132
• Flexi-funded or residential Aboriginal Aged Care hostels or nursing homes	55
• Newsletter respondents (people who had responded to the previous newsletters wishing to contribute)	43
	230
Total	513

A summary of the results of the Stage 6 'Needs' questionnaire is provided at Appendix 7. The results strongly mirror the same issues and concerns identified in the field work. The information elicited by these questions has been incorporated into this report.

1.8 Data analysis

Most of the data gathered was of a qualitative nature. Data from questionnaire responses was reviewed and summarised under the question headings. After analysis of field notes from eight locations in Victoria, South Australia and Queensland and bearing in mind the questionnaire responses, a common reporting format was devised using headings grouped under the following main themes.

1. Models of service delivery
2. Discharge planning
3. Information
4. Education
5. Communication
6. Traditional Issues
7. Counselling and bereavement issues
8. Place of death, funerals, 'sorry business' and repatriation of deceased
9. Resources – and funding issues
10. Medication
11. Marginal social conditions
12. Equipment
13. Role of AHWs, ALOs, Aboriginal HACC workers
14. Confidentiality
15. Access of Indigenous people to palliative care services

16. Administration of the Indigenous status question
17. Referrals of Indigenous people to palliative care
18. Care planning and delivery
19. Importance of service provider networks and the need for a team approach
20. Access to and value of palliative care specialist consultants
21. Cultural awareness training
22. Volunteers and volunteer training
23. Palliative care in aged care facilities
24. Palliative care in nursing homes
25. Eligibility for palliative care
26. Aspects of good and bad practice

Field notes were reviewed and reported under these broad headings with some variation in sub-headings which reflects variations from place to place. These notes and the questionnaire response summaries were reviewed to produce this report. Issues relating to the analysis of data about rates of access are discussed in Chapter 4.

1.9 Reporting

Three interim reports were prepared and delivered at the end of stage 2, stage 5 and at stage 8. Steering committee meetings were held by phone hook-up (2 meetings) for reporting and discussion of field destinations. The steering committee's input was solicited by email on issues such as methodology, newsletter text, and other issues as they arose.

At the end of stage 8 the contract was varied to allow for the production of an additional newsletter, primarily to provide more rapid and substantial feedback to people who had taken part in the fieldwork.

As requested by the funding agency, the field notes were transcribed and typed and a de-identified version of the notes was supplied for use by the Wodonga Project/Mungabareena National Guidelines project.

Because of the nature of our agreements with participants not to disclose information about communities and individuals, the field notes will not be published. Voices of community participants have been quoted at length in this report in ways which do not identify specific communities or individuals.

A fourth and final newsletter will be produced on acceptance of this report. Each newsletters was posted to approximately 1500 people and placed on the project web site at <http://member.telpacific.com.au/ksa>.

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Chapter 2

National survey of palliative care provision



Many people know little about palliative care and how and where it is delivered. We have therefore documented what we discovered about the services that exist around Australia.

2.1 Introduction – variation of models

Mainstream palliative care services in most States and Territories include palliative care beds in a small number of metropolitan hospitals and a network of palliative care coordinators and community-based services, which usually operates as part of the State Government's regional health delivery structure. In some metropolitan centres there are separate palliative care units or hospices, often run by private service providers.

The community-based services either include, or coordinate access to, services to deliver palliative care in the home: services such as palliative care nurses, social workers, grief counsellors and home help. Some regional hospitals also have limited palliative care beds, usually in surgical or acute wards. The structure of palliative care service delivery in Western Australia, South Australia and Queensland is outlined in recent comprehensive reports or strategies¹.

A snapshot of several States illustrates the variation that exists not only from State to State but within States.

2.2 Palliative care in Queensland

The services available in Queensland, as in other States, are comprised of the following major components (Adams and Schweizer 2001):

- tertiary hospitals, palliative care consultative services and designated palliative care in-patient facilities
- community based services
- general practitioners

The level and range of palliative service available throughout the State vary considerably, with notable differences between urban, rural and remote areas.

¹ (1995). Palliative Care in Western Australia to the Year 2001, Part One, 'Metropolitan Area', Health Department of Western Australia. and (1996). Palliative Care in Western Australia to the Year 2001, Part Two, 'Country Services', Health Department of Western Australia.

Adams, E. and Y. Schweizer (2001). Palliative Care in Queensland – Issues and Initiatives, Palliative Care Queensland. Volume 1: 1-123. and Adams, E. and Y. Schweizer (2001). 'Palliative Care in Queensland – The State Defined.' Volume 2: 1-124.

Cooper, G., M. Horsell, *et al.* (2001). 2001 Report to Parliament on Palliative Care in South Australia, Department of Human Services SA: 1-27.

2.2.1 Tertiary hospitals, palliative care consultative services and designated palliative care in-patient facilities

Most of these palliative care specific services are concentrated in the south-eastern and coastal areas of the State, though most of the districts within the areas defined as Regional, Coastal and Urban provide either tertiary hospitals, palliative care consultative services and/or designated palliative care in-patient facilities. The availability of palliative care specific services in the rural and remote areas of the State especially in central and northern Queensland is limited (Adams and Schweizer (2001) (p19).

2.2.2 Community based services

There is great variation amongst the providers of community-based services and in the distribution of these services within the State (Adams and Schweizer 2001) (p21). In most areas, community-based services include one or more of the following main domiciliary providers: Blue Care, St Luke's Nursing Service and St Vincent's Community Services; as well as some independent or private domiciliary providers such as The Green Nurses in Townsville. Community and District Health Services also provide some palliative care in rural and remote areas, including clinics, Community Aged Care Packages (CACPS) and Community Options (COPS) in isolated areas.

In Gordonvale, south of Cairns, a decommissioned hospital is now the base for a palliative care service providing 14 in-patient beds and community nursing services. This service has close links with the local Aboriginal community. The service also has provided training for Torres Strait Islander health workers, based on Thursday Island.

An analysis of the distribution of community-based palliative care services using data from Adams and Schweizer (2001) (p21 and p39) indicates that:

- in metropolitan Queensland there are 12 community based palliative care services in three health districts;
- in Regional, Coastal and Urban regions there is one service in each of seven districts out of a total of 15 districts);
- in rural and remote regions there is one service in each of four health districts out of a total 16 districts.

2.2.3 General practitioners

Adams and Schweizer (2001) paint the GP as the key primary provider of palliative care in the home. They point out that most GPs have very few palliative care patients in any one year and that this creates difficulties in care provision by GPs and in the coordination of seamless care.

Other key aspects of the system include the use of:

- other (non tertiary) hospital facilities, especially in rural areas;
- residential care facilities;
- respite services allied health;
- bereavement support (usually built into most palliative care services) and pharmaceuticals and equipment;
- volunteers; and
- community education and awareness programs.

2.2.4 Indigenous palliative care in Queensland

There are no Indigenous-specific palliative care services in Queensland. As far as could be established, only one palliative care service provider employs an Indigenous staff member (an Aboriginal Liaison Officer).

There are two partnership agreements between States and the Australian Government concerning Aboriginal and Torres Strait Islander health in Queensland: one covering the Torres Strait region; and one for the mainland. These are broad, general agreements covering issues relating to access to mainstream services, maintenance of Indigenous-specific services and coordination issues. They have given rise to Partnership Forums which have developed Frameworks for Action documents which identify particular areas of need for Indigenous health. Palliative care is not mentioned in these framework documents².

Aboriginal and Torres Strait Islander health services in Queensland are delivered either by Aboriginal and Islander Health Services as part of the Community Health system, or by Community Controlled Health Organisations (usually referred to as AMSs or AHSs), some of which affiliate under the banner of the Queensland Aboriginal and Islander Health Forum (QAIHF).

Some AMSs have some palliative care clients. In Brisbane, the Aboriginal and Islander Community Health Service at Woolloongabba provides no specific palliative care service but works closely with the Mt Olivet Palliative Care Service. In Cairns, the Wuchopperan Medical Service provides clinical, cultural and carer support to palliative care clients, as well as bereavement and grief counselling through its Social Health Team. Wuchopperan doctors consult with the palliative care unit based at Cairns hospital, but have no formal after hours service.

Some AMSs have nurses who provide home visits, but most are 9.00 – 5.00, five days per week services and offer no after hours service. Other AMSs report that they *'have no resources to pick up palliative care but would like to work with other service providers'*.

Some mainstream palliative care services in Brisbane contact the AMS at Inala or the Aboriginal and Islander Community Health Service at Woolloongabba if they have an Aboriginal or Torres Strait Islander client. The Princess Alexandra Hospital palliative care unit will contact the Inala Community Health service to ensure services are put into place for the client on their return home.

State-run Aboriginal and Islander Community Health services provide no specific palliative care services but some services will make home visits to palliative care clients if requested. This may occur if one of the palliative care hospitals in Brisbane contacts them about a palliative care client.

Whilst some hospitals employ ALOs, they may not be directly involved with palliative care clients or with discharge planning. As far as we are aware, none of the domiciliary nursing services (important partners in palliative care provision in the home) have Indigenous staff as yet, though we have been advised that Blue Care has engaged an Aboriginal Employment Officer.

The Aboriginal and Islander Women's Cancer Prevention and Support Service is an important resource in Indigenous palliative care. This service is disease-specific and provides important support to clients, many of whom are palliative care clients and who are older women who have presented late via the Oncology Unit.

Established and collaborative relationships between palliative care service providers and Aboriginal health service providers would be the exception rather than the rule.

² Queensland Department of Health.

2.3 Palliative care in New South Wales

In each of the 17 health service regions of the State there is a Palliative Care Service headed by a Palliative Care Director, CNC or CNS Palliative Care. These units typically coordinate palliative care services in their regions, providing consultative services, liaising with in-patient facilities and coordinating community nurses, volunteers, allied health and home help services. Some of the regions have several sectors or sub-districts which may each have a palliative care coordinator. In-patient facilities vary, from beds in public hospitals to dedicated hospice facilities, both public and private.

Each of the 17 health service districts also has a director of Aboriginal Health who contributes to policy and planning in relation to Aboriginal Health and coordinates the work of health workers, much of which is focused on health promotion and education.

Each health region has begun the development of a Palliative Care Strategic Plan. Of the four strategic plans reviewed, all included Indigenous peoples as special client groups and had identified actions aimed to improve access. The Regional Director of Aboriginal Health had been actively involved in the planning process for one of the strategic plans, but it appears that the Regional Directors of Aboriginal Health and the relevant AMSs had not always been actively involved in the planning process for the strategic plans.

Our scoping study and field interviews indicate that at the local level there is little contact between palliative care units and AMSs or Community Health based AHWs. There are no Indigenous-specific palliative care services. Rather, AMS doctors tend to manage those of their clients who require palliative care and are unlikely to refer them to specialist palliative care services. AMS services are usually 9.00 – 5.00, five days per week services.

The New South Wales Aboriginal Health Strategic Plan (1999)³, produced as a result of the New South Wales Health Partnership Agreement, does not specifically mention palliative care. Most palliative care services have little knowledge of the needs of Indigenous people, nor do they have relationships with Aboriginal and Torres Strait Islander health service providers.

2.4 Palliative care in the Northern Territory

The Northern Territory Health web page states that palliative care is '*shared by family/partners, health services and community organisations*'. Education, support and consultation is provided to clients, service providers and the community by members of palliative care teams.

Palliative care teams based in Darwin and Alice Springs provide:

- client assessment;
- facilitation of care coordination (case management);
- advice, counselling and support for clients;
- direct specialist care and consultancies;
- access to services of medical officer, nurse, allied health professionals, pastoral care and volunteers;
- telephone support and advice to clients and health care providers 24 hours per day, seven days per week bereavement services;

³ (1999). New South Wales Aboriginal Health Strategic Plan 1999, State Health Publication No: (AH) 990151, NSW Health Department.

- community education;
- education for service providers;
- access to equipment; and
- access to dedicated palliative care hospital beds.

An interdisciplinary palliative care team may include people from public, private and non-government community organisations. Services may include:

- medical care;
- nursing care;
- culturally relevant care;
- allied health professional care;
- respite care;
- hospital care;
- hospice care;
- care in nursing homes and hostels;
- personal care;
- spiritual care;
- home support; and
- transport.

2.4.1 Eligibility

Any person of any age in the advanced stages of a life threatening disease where cure is no longer possible is eligible to access palliative care along with their family, partner and carers.

2.4.2 Referral

Referral to palliative care can be made by:

- self referral;
- family members and friends;
- general practitioners;
- specialists;
- community health nurses; or
- other health professionals.

2.4.3 Indigenous palliative care in the Northern Territory

There are no Indigenous-specific palliative care services in the Northern Territory. The Territory is essentially covered by two palliative care services, the Top End Palliative Care Service (40% Aboriginal

and/or Torres Strait clients) which operates out of Darwin, and the Territory Palliative Care Service which operates from Alice Springs (50% Aboriginal clients). One Aboriginal staff member is attached to the Top End service.

The Top End Palliative Care Service is a consultative service providing education and support to health practitioners in the community and in hospital settings, as well as clients, carers and families in urban Darwin, rural and remote areas, East Arnhem and the Katherine region. Outreach services are limited because of the cost of getting staff into remote communities and the lack of accommodation. It employs an AHW as well as doctors (2), nurses (3), part-time occupational therapist, part time pastoral care worker, administration staff (2) and a full time social worker.

Danila Dilba Aboriginal Health Service in Darwin also provides some palliative care services in the Darwin area and works in conjunction with the Top End Service to provide a coordinated approach to care. Although the Aboriginal health service receives no palliative care funding, they recorded a total of 20-25 palliative care clients during 2000/2001. The Aboriginal health service and Top End Palliative Care Service meet at least every four weeks to discuss mutual clients.

2.4.4 Regional and remote areas

Remote regions such as East Arnhem can be cut off for six months at a time due to seasonal weather conditions and Aboriginal health services there report that regionally based respite and palliative care services are badly needed.

In the Tiwi Islands the population of approximately 2,400 people form a distinct language group. Palliative care is provided here by the extended family (mothers, fathers, children, husband, wife, aunts, uncles) with support from health service staff including doctors, nurses and AHW's. There is a large health clinic with a staff of 50 in the main population centre on Bathurst Island and two clinics on Melville Island. The clinics are directed by the Tiwi Health Board and are managed by senior Aboriginal health workers who oversee the work of nurses, GP's, program managers and visiting specialists. The registered nurse and AHW from the Top End Palliative Care Service in Darwin are available as required and a physiotherapist visits regularly.

The Territory Health Palliative Care Service based in Alice Springs provides case management of clients in Alice Springs and an outreach consultative service to outlying remote Aboriginal communities in its region in the Northern Territory, South Australia and Western Australia. It offers support, advice and education and works on an empowerment model by assisting local health staff to work out solutions. The service employs a male RN Coordinator, a female RN and a part-time female medical officer who has extensive experience working with Indigenous palliative care clients. This service has no Indigenous staff. Despite the large number of Aboriginal clients (50%) it has been unsuccessful in attracting funds for Aboriginal positions.

Some services are also provided to palliative care clients in central Australia by the following Aboriginal organisations:

- Central Australian Aboriginal Congress (CAAC) (an AMS);
- Arrente Council;
- Tangentyere Council;
- Old Timers Nursing Home;

- Home Help Alice Springs;
- Hetti Perkins Nursing Home.

The Territory Health Palliative Care Service works closely with the Central Australian Aboriginal Congress, Frail Aged and Disability Service team and the Tangentyere Council Homemakers and Old Peoples Services (HOPS) team. The Congress Health Worker accompanies the Territory Health Palliative Care Service staff on all initial visits to Aboriginal palliative care clients in Alice Springs.

The Tangentyere HOPS program has two HACC workers. A full time CACP carer is responsible for providing services to clients in 22 town camps and a 'share house' of 6 clients. They also work closely with the Palliative Care Service and CAAC. Their specific role in providing palliative care services is to arrange and deliver special food to the client (cooked by the Alice Springs Hospital), monitoring medication dosette boxes and ensuring their wardens keep an eye on clients during their day and night patrols.

In another town in the region the hospital employs a part time nurse to provide palliative care and receives support from the Territory Health Palliative Care Service based in Alice Springs. The Aboriginal Medical Service in the town cares for palliative clients as needed.

Representatives of Aboriginal organisations in Alice Spring recommended that a male and female AHW be employed to work with the palliative care team, but suggested they be physically located in an Aboriginal organisation (possibly AMS) so they would not be working in isolation. They suggested that at least two full time Aboriginal employees (male and female) were needed, but ideally three should be employed to carry the responsibility, and that these should be trained in palliative care and rotated throughout the year to avoid 'burn out'.

The majority of Aboriginal people living in remote communities are unable to access government supported palliative care services.

2.5 Palliative care in Tasmania

'The Tasmanian Palliative Care Service is a specialist State-wide service that each year provides direct care, assessment and ongoing involvement and advice to approximately 1000 individuals, and their families.

'Funded through the Tasmanian Department of Health and Human Services and part of the Division of Community, Population and Rural Health... the Tasmanian Palliative Care Service provides specialist medical, nursing and social work expertise and trained volunteer support to people with a life-limiting illness, as well as to their families.

'Palliative care is offered directly to people in need or indirectly through the provision of education, consultancy and information to health professionals who are essential to the delivery of palliative care.

'The Tasmanian Palliative Care Service has three specialist community teams based in Hobart, Launceston and Burnie, with outreach to rural and urban areas.

'The service funds a 10-bed in-patient facility (J W Whittle Palliative Care Unit) in Hobart, and three State-funded beds at Phillip Oakden House (the Manor hospice) in Launceston, with a commitment to extend in-patient facilities in the North West. The Whittle Unit provides care to public, private and Department of Veterans Affairs clients. People are admitted to Whittle via referral from a medical practitioner to one of the palliative care medical specialists.

‘The medical director of the Tasmanian Palliative Care Service and two palliative medicine specialists hold conjoint positions with the University of Tasmania, recognising the importance of research and undergraduate and post-graduate palliative care education.

‘Palliative care teams work collaboratively with the Hospice Care Associations (South and North West). The Hospice Care Associations provide trained volunteer support to families and people in need of palliative care.’⁴

2.5.1 Indigenous palliative care in Tasmania

Aboriginal health services are provided by The Tasmanian Aboriginal Corporation and the South East Tasmanian Aboriginal Corporation (SETAC). SETAC informed us that Aboriginal people in Tasmania access mainstream services without difficulty. Palliative care service providers in Hobart report that The Tasmanian Aboriginal Corporation medical service is involved if desired by clients. For Cape Barron Islanders, however, remoteness means that people usually have to travel to the Tasmanian mainland for treatment and care and usually pass away there.

The Tasmanian Aboriginal Health Framework agreement does not include any reference to palliative care.

2.6 Palliative care in Victoria

Delivery of palliative care in Victoria is divided between five regional palliative care units in the country and four palliative care units in metropolitan Melbourne. A typical region might coordinate four or five sites within it. These sites are coordinated by Clinical Nurse Specialists (CNS) who take referrals, assess patients and coordinate care plans. Care will be delivered wherever is appropriate – at home, in a hospital or in a nursing home or hostel. There will usually be a general after hours telephone information and advice service and sometimes patients are put ‘on-call’ giving them direct phone access to nurses after hours. Services available include:

- advice or assistance to manage distressing symptoms (eg. pain, nausea, vomiting);
- a central information point for advice;
- coordination for support services in the community and between hospital and home;
- access to respite care;
- emotional support to patients’ families and carers;
- specialised equipment loans;
- grief and bereavement support.

CNS services are free and funding is available for a range of other services where these are deemed necessary, for example:

- residential care;
- short term respite care;
- nursing care;
- personal care attendants;

⁴ Drawn from Tasmanian Government website www.dhhs.tas.gov.au/palliativecare.

- allied health care;
- pastoral care and counselling;
- home help;
- travel costs;
- complementary therapies;
- equipment hire and dressings and pharmacy.

Eligibility criteria include:

- person has been diagnosed as having a life limiting illness;
- a progressively deteriorating disease;
- a life expectancy of six months or less, or requires earlier support in facing a significantly foreshortened life expectancy.

Variations from this model exist, for example some palliative care services are brokered out to private suppliers.

2.6.1 Indigenous palliative care in Victoria

There are Aboriginal community controlled health organisations throughout Victoria, 27 of which are affiliated with the Victorian Community Controlled Health Organisation (VACCHO) umbrella body. Some of these have developed relationships with local palliative care service providers but this is the exception rather than the rule. There are 18 Koori Liaison Officers (ALOs) in hospitals throughout Victoria.

A draft report prepared in 1997 (Wagstaff 1997) assessed the situation regarding Indigenous palliative care in Victoria at that time. This report is summarised in Appendix 5. Little appears to have changed in the intervening period.

The Victorian Koori Health Framework Agreement does not include any reference to palliative care.⁵

2.7 Palliative care in South Australia

In South Australia, palliative care can be provided in a person's home, community-based residential settings, in-patient units or acute care units.

2.7.1 Acute care

Patients in acute care facilities (hospitals) are managed by their treating specialist, with palliative care specialists providing consultancy. In rural health units, there has been a trend toward developing family suites that provide greater opportunity for family members to actively participate in the care of a person who is dying.

⁵ Victorian Department of Human Services (Pers Com).

2.7.2 Community care

Community palliative care is provided by all public palliative care services in South Australia, offering a range of supports for people remaining in their place of residence.

2.7.3 Hospice care

Hospices provide intensive in-patient care, day care and support, including respite care and short-term admission to stabilise symptoms or provide in-patient care when death approaches and community care is not viable. Care may be provided in a freestanding building or a separate special purpose area within a hospital.

2.7.4 Public hospitals

Most major metropolitan hospitals have palliative care beds. This may be a converted area within a ward or unit, or patients may be managed in a general ward.

2.7.5 Palliative care services

There are five metropolitan specialist palliative care services providing in-patient and community based care. The following provides a summary of these services.

Each of the five palliative care services (PCS) is focused around a hospital which has in-patient facilities. The palliative care teams based at these five hospitals coordinate the services of the in-patient units, the community nursing service and the domiciliary care providers, liaising with hospices and ancillary services as needed. For example:

Lyell McEwin PCS:

- forms the northern arm of North Western Adelaide Health Service (NWAHS) PCS;
- provides a team management approach to the care of palliative patients;
- consults with community-based clients and Central Districts Private Hospital;
- provides outpatient services and psychosocial support, counselling, respite care, and bereavement program with close liaison and availability of shared-care with a consultant psychiatrist;
- medical consultants share an after hours telephone service for clients with the western arm of the NWAHS;
- provides an on-call palliative care doctor;
- provides a community outreach program, maintaining close working relationships with general practitioners Royal District Nursing Service (RDNS), Domiciliary Care Service (DCS) and other community services.

Two organisations which are central to the service provision of the palliative care services are the RDNS and the Domiciliary Care Service.

Royal District Nursing Service (RDNS):

- has three palliative care nursing groups – central, southern and northern – that care for 550 patients per month;
- has specialist and generic nursing service that supports patients dying at home;
- has specialist palliative care clinical nurse consultants (CNCs) who provide palliative care and liaise with other palliative care services;
- has field nurses who provide daily general palliative care nursing care in consultation with specialists and palliative care CNCs;
- provides pain and symptom management, general nursing care, carer support and bereavement care;
- has public and private liaison nurses to facilitate discharge planning for clients;
- provides a 24 hour call centre which streamlines referrals to ensure clients, carers and referral agencies receive a timely response from specialist nurses.

Metropolitan DCSs:

- underpins and supports the work of other agencies;
- the three metropolitan DCSs – Southern DCS; Eastern DCS; Northern DCS – provide case management from allied health and nursing clinicians;
- has case coordinators which work with palliative services and RDNS;
- has clients who require palliative care services from clinicians best able to meet the care needs;
- provides clinical assessment (occupational therapy, physiotherapy and some social work), nursing care, equipment provision, environment modification, some respite care and home help;
- provides a consultancy service to other clinicians within DCS.

In addition to these services, the Women's and Children's Hospital (WCH) has a paediatric palliative care liaison nurse supporting PCS providers who deliver home-based palliative services to paediatric patients and their families. It offers home-based palliative care for dying children, including 24 hour on call support, and provides bereavement support for parents and siblings where no other appropriate services are available.

Rural services

There are no nominated palliative care beds in rural regions, but local hospitals have developed small suites or comfortably furnished rooms which greatly increase the capacity for family members to participate more actively in the care of the dying person.

In the country, palliative care services are sited within regional government health services and there are several palliative care services within some regions.

A rural palliative care service typically:

- provides some direct care for palliative care patients;
- coordinates care needs with local community providers;
- provides consultancy to local health units and community outreach services that do not have dedicated palliative care workers.

For example, one region has:

- a palliative care consultant who provides some direct care, education, and visits the hospital as a consultant;
- a clinical nurse who provides counselling, symptom management and case management and staff who provide nursing to palliative care clients;
- a bereavement coordinator who provides a counselling service for patients and families; and
- provides allied health services (social worker, physiotherapist, dietician, occupational therapy, equipment etc) that are coordinated through the health centres

In contrast another has only:

- a palliative care nursing service which provides a consultancy role to generalist providers and works with complex cases;
- a bereavement support worker to coordinate bereavement services and develop the role of volunteers; and
- has out of hours support managed by GPs.

REGION	PALLIATIVE CARE SERVICES
Eyre	Pt Lincoln & Lower Eyre Palliative Service
Hills, Mallee, Southern	Hills Mallee Southern Region District Nursing Service South Coast Palliative Care Service Murray-Mallee Palliative Service
South East	Mount Gambier & District Palliative Care Service Naracoorte & Lucindale Palliative Care Service
Mid North	Port Pirie Palliative Care Service Laura & Districts Hospital
Northern & Far Western	Whyalla Palliative Care Service Port Augusta Palliative Care Service
Riverland	Riverland Palliative Care Service
Wakefield	Barossa & Districts Palliative Care Service Northern Yorke Peninsula Health Service Gawler Palliative Care Service

2.7.6 Aboriginal health services

Aboriginal health services in South Australia include community controlled health organisations⁶ and South Australian Department of Human Services Regional Community Health Services Aboriginal Health Teams (for example Muna Paiendi based at Lyall McEwin Hospital, The West Nunga Health Team at Angle Park in Adelaide, and others set in rural areas). Some hospitals have ALOs but these are not necessarily (or usually) involved in palliative care planning or service delivery.

⁶ There are 26 affiliated members of NACCHO (for example Nunkuwarin Yunti in Adelaide and Pika Wiya in Port Augusta).

The South Australia Aboriginal Health Partnership Agreement⁷ does not mention palliative care, however it does include improvement of Aboriginal access to all mainstream services as a major strand.

In metropolitan Adelaide, the palliative care service providers do not have much knowledge of Aboriginal health services, whilst Aboriginal health service providers appear to have very limited knowledge of palliative care services. Few established relationships exist, though there have been cases where the AMS has operated as a case coordinator, bringing in palliative care services as required. AMSs and Aboriginal Community Health Services are 9.00 – 5.00, five days per week services.

In remote areas, community clinics are the main service providers. For example, Nganampa Health Council is an Aboriginal (Anangu) community controlled health organisation providing primary health care services to people living on the Anangu Pitjantjatjara (AP) Lands, in the far north-west of South Australia. There are six main clinics and three health worker stations in smaller communities across the AP Lands.

The administrative centre of the Nganampa Health Council is based at Umuwa, 470 kms south-west of Alice Springs while an office in Alice Springs handles finance, supply and purchasing, personnel and payroll, mail services, data entry and program coordination.

As well as providing 24 hour primary clinical care, Nganampa Health delivers a range of public health programs including aged and disability care. The *Tjilpi Pampa Ngura* was opened at Pukatja in October 2000 and is part of the Multi Purpose Service funded by the Australian Government Department of Health and Ageing. It provides short-term care (up to 2 months) for respite and convalescence for older Anangu, and stores and distributes palliative care equipment (purchased some years ago with a one off grant) to communities as required.

Nganampa Health also has Home and Community Care (HACC) funded services in six communities. In Pukatja the HACC program is run from the *Tjilpi Pampa Ngura*. The program delivers meals and laundry services to older Anangu from Pukatja and surrounding homelands, who also visit the facility for the day on a regular basis, where they are assisted with showering and provided with a cooked meal. In other communities basic HACC services are provided, including a cooked meal five days a week, laundering of bedding and clothes, provision of firewood and transport from camp to store, clinic and office.

For specialist treatment, people from the AP Lands are required to travel to Alice Springs or Adelaide. Nganampa Health Council coordinates assistance to people requiring specialist treatment, by providing airfares, bus fares, transport and accommodation, interpreters and hospital liaison services.

Palliative care has been identified as an important need on the AP Lands. A strategy for developing palliative care for Aboriginal Australians was prepared for Nganampa Health by Robyn Mobbs (1996) as part of a national palliative care project funded by the Australian Government Department of Health and Family Services in 1996.

A report by Bourke, *et al* (1998) is the final report of a Australian Government funded investigation into the feasibility of an Aboriginal Palliative Care Strategy for South Australia.

⁷ SA Aboriginal Health Council.

2.8 Western Australia

The system and structure of palliative care in Western Australia is different from other States. Initiatives in palliative care in Western Australia have come almost exclusively from the private sector and 75% of palliative care services are provided by the private sector. However this seems to have resulted in an uneven distribution of services, which are strong and integrated in some areas, but have gaps in other areas.

The main palliative care services in Perth consist of:

- palliative care units in hospitals such as Royal Perth and Sir Charles Gardener (Monday-Friday) using a 'roving model' within the hospital (ie not 'bed based')⁸;
- several hospices such as The Cottage Hospice, Hollywood Private Hospital Palliative Care Unit and the Murdoch Community Hospice. The Cottage Hospice and Murdoch provide admission for symptom control, respite care and terminal care. The average length of stay at the Cottage Hospice is 12-14 days and the mode⁹ is 1 day. People generally come to these facilities because they cannot die at home – either because the family cannot cope or because of the complexity of their symptom management;
- Silver Chain Hospice Care Service provides domiciliary palliative care for metropolitan Perth, including consultative and direct support in the patient's own home or in hostels. They provide a 24 hour service with CNCs on call. There are eight Silver Chain teams in the metropolitan area. Each team consists of nurses, care aids, doctors (Silver Chain employs 30 GPs), volunteers, a counsellor, a chaplain and a specialist palliative care consultant. All Silver Chain nurses have palliative care training.

The Aboriginal Medical Service, Derbal Yerrigan, does not have specialised palliative care services or staff. It employs 150 staff over seven sites, including four community nurses, six care aids, nine Aboriginal health workers, three senior health workers and 8.4 (effective full time) doctors. It also provides physiotherapy, podiatry and dental services, and employs a mental health nurse and social worker. Derbal Yerrigan has a transport service and provides access to a range of other specialists. They see themselves as playing a coordination role with Silver Chain which provides services outside normal working hours. Derbal Yerrigan sometimes receives referrals from Royal Perth if one of their doctors has been involved with the client.

The AMS does not keep data on palliative care client numbers but believes there are currently 11 cases at its Maddington site (two are renal clients and some of the nine others may be elderly¹⁰). There are also 13 HIV positive clients.

One hostel (36 beds) caters for long term renal clients from remote areas who are in Perth for dialysis.

Currently, there are virtually no Indigenous-specific mental health services in Perth and none which specialise in grief and loss care. Aboriginal people do not access mainstream bereavement services. The Aboriginal Medical Service hopes to employ psychologists on its staff in the near future.

⁸ For example the palliative care team at Royal Perth do not have any in-patient beds. They provide a consultative service to in-patients and their role varies depending upon the medical team with whom they are working. As a rule they do not have patients under their own care. Patients are referred to the unit by doctors (doctor to doctor) or by nurses (nurse to nurse). A large part of the role of the palliative care team is to advocate for what the patient needs and for the involvement of the palliative care team.

Sir Charles Gardener Hospital has a similar system though they have access to two palliative care beds for emergencies. These are rarely used, however. The Charles Gardener Palliative Care Team also runs an outpatient clinic three times per week for symptom management.

⁹ Most common length of stay.

¹⁰ Many people working in Indigenous health do not distinguish between palliative care and care of the frail aged.

One small unfunded service has put together what the staff believe to be culturally sensitive processes. Most staff at this centre do not have formal tertiary qualifications.

2.8.1 Eligibility

Sir Charles Gardener Hospital eligibility criteria include complex physical or emotional symptoms related to a life-limiting illness. 90% of clients use the facility for three months. Sir Charles Gardener Hospital also undertakes symptom management while patients are undergoing curative treatment.

2.8.2 Contact with Aboriginal health and community organisations

The Western Australian Commonwealth–State Health Partnership Agreements on Aboriginal Health do not specifically mention palliative care, though they address the issue of improving access to mainstream services and coordination issues.¹¹

One Perth hospital employs no Aboriginal liaison staff, while the other employs a number of Aboriginal liaison officers and an Indigenous clinical advisory nurse (ICAN). This position is an innovation. The ICAN acts as a medical advocate, checking patients' understanding of their situation and assisting with communication. She works closely with the palliative care team.

A mainstream service provider reported that there are limited or non-existent relationships with Aboriginal service providers and there are no regular contacts with Aboriginal health organisations. There are no formal or regular meetings between the palliative care team and the hospital ALOs or the ICAN. Contact is on an as-needs basis and is made with the community organisations or the AMS when someone is going to go home to the community or it is necessary to talk to the wider family.

The Aboriginal Hospital Liaison Unit (funded by the State government) provides a vital service to remote area clients, especially where the hospital has no Aboriginal staff.

2.8.3 Metropolitan/remote areas relationship

Aboriginal Hospital Liaison Unit

All Aboriginal patients from remote areas are referred to this service. A remote area is anywhere outside of a regional town. This unit provides discharge planning for all remote area Aboriginal clients for all Perth public hospitals. Clients are not referred to local palliative care services but to their local or regional hospital.

The service visits patients in Perth hospitals and twice weekly provides a brief report back to their referring hospital in the region. This usually contains some information for family as well as medical information. When a patient is ready to be discharged the Aboriginal Hospital Liaison Service arranges their discharge and travel back to the local hospital, or regional hospital if there are no beds at the local hospital. They ensure that patients are met from the bus or plane. Patients are repatriated using QANTAS flights, not the Royal Flying Doctor Service (RFDS).

If patients require palliative care then every effort is made to get them back to their 'country'. If someone is *non compos mentis* or cannot go home for any reason then, in consultation with the patient's family,

¹¹ WA Department of Health (Pers Com).

they may be referred to a C-Class nursing home in Perth. This must be a family decision. This situation generally rises once or twice a year.

Repatriation of deceased people is now paid for by the Department of Health.

The clients who most need the services of this unit are from the Kimberley and the Pilbara.

About 1000 remote area Aboriginal patients a year come to Perth, and about 800 of these go to Royal Perth. Of these possibly five per year would be considered palliative care patients. These clients would be referred to the local hospital (eg Halls Creek or Fitzroy Crossing) and if there were no beds there, then to the regional hospital – such as Derby. If they go to Derby and can't go home then they may go to Numbla Nunga, an Aboriginal nursing home in Derby.

At any one time there are about 40 Indigenous patients from remote areas on renal dialysis in Perth. These patients either die in Perth or are discharged to a location where there are dialysis machines and travel to Perth as needed. If dialysis patients decide to discontinue treatment they will be sent home, however when these patients become ill in the community the nurses, usually under instruction from family members, will call the RFDS and they will be flown back to the local or regional hospital. This is an ethical issue for the nurses who feel they have an obligation to do what the family asks – especially when the patient is unconscious.

There are many stories of patients being brought to Perth for treatment when such treatment was pointless and then being unable to return home to die. There were also stories of renal patients coming to Perth for treatment without fully understanding that the treatment would require them to stay in Perth for the rest of their lives. Lack of facilities in remote areas sometimes means that the medical profession takes the view that *'they can't go home – there is no one there to look after them'*. It would be preferable to ask either: *'what would have to be done or put in place to allow these people to go home and how could that be achieved?'*; or: *'knowing what you will face, would you prefer to go home even though there are no facilities?'*

There are no Indigenous-specific nursing or aged care facilities in Perth.

The Palliative Care WA (Inc) *Palliative Caring at Home* booklet indicates that there are 18 country locations which have palliative care services. Five of these are regional services which have three or four sites or service providers within them (ie there are an additional 12 services providers). The models of delivery in these areas vary greatly. For example:

- In Geraldton there is a tripartite arrangement between the St John of God Hospice, Silver Chain, and the hospital under the auspices of an incorporated body called the Geraldton Palliative Care Service. This arrangement receives funding from the State Government, but not enough to cover equipment or capital costs.
- In Kalgoorlie there are palliative care beds and trained palliative CNCs at the hospital who are funded to provide a consulting service, but there is no hands on home-based palliative care nursing. A volunteer organisation is funded to provide some home visiting. An education and consulting position is funded (by the Cancer Foundation) for cancer patients.
- In the Kimberley, palliative care has been delivered across the region by the Kimberley Palliative Care Service, which is a network of community-based palliative care teams located in several population centres across the region. These teams (some with Aboriginal members) generally consist of volunteers and palliative care nurses (community nurses) whose after hours work is funded through the State by the Australian Government's Palliative Care Program and administered by the Kimberley Health

Service through the Division of General Practice. Networks such as this are readily affected by staff changes, particularly of key coordinators. A new palliative care service which will be administered by the Kimberley Health Service (as part of its Population Health Program) is being set up, broadening the scope of the existing model to provide consistent clinical support, care coordination, education and a more comprehensive coverage. It has been suggested that there is a need to fund palliative care positions in the Aboriginal Medical Services in some population centres in this region to become part of this palliative care network.

2.9 Palliative care in the ACT

In the ACT there is a home-based palliative care program and a hospice at Clare Holland House. The home-based service works closely with the hospice and offers nursing and allied health services to patients at home, and a consultative service to residents of aged care facilities. A non-government volunteer program is also run from Clare Holland house. There are no Indigenous volunteers.

2.10 Findings and implications

We set out to discover what sort of services are available to and are being accessed by Aboriginal and Torres Strait Islander people. This chapter records what we discovered about palliative care services around Australia. It is not a comprehensive study of all palliative care services and there are gaps in the information that we gathered.

What is clear however is that the structure and operation of palliative care services varies markedly for State to State and from region to region and that there are very few if any Indigenous-specific palliative care services.

Nationwide, only two services employ Indigenous palliative care staff to work specifically with Indigenous clients. Most of the palliative care services do not have any working relationships with Aboriginal and Torres Strait Islander health services (where these exist).

Most Aboriginal and Torres Strait Islander health services (community-controlled or government-run) do not consider themselves to be palliative care service providers and though most attempt to manage their clients' illness through the terminal stage, they do this without expertise, training or support. These services are 9.00 –5.00, five day a week services and are not linked to any palliative care service.

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Chapter 3

Socio-economic and cultural contexts



Some families are prepared to look after [the] sick person. General nursing can be heavy going. Some families want to do the caring but find it is a different story in reality – its too much hard work. Sometimes if there is no family to look after an old sick person, the community will nominate someone and top up their CDEP. On odd occasions family are willing and have the community nurse if they get ‘unstuck’ – maybe if the catheter falls out. Have seen situations where the family will take someone home and a week later ring up and say they can’t do it anymore. [Aboriginal RN – remote community, Western Australia]

3.1 Introduction

A feature of Indigenous history and culture is the variation in cultural traditions across different regions. At the time of invasion there were some 600 Indigenous languages, reflecting the level of cultural variation at that time. Aboriginal and Torres Strait Islander cultures are alive, and like other cultures are subject to change and development.

The purpose of this chapter is to try to provide some background information for service providers and policy makers about the context of planning and delivering palliative care services to Indigenous communities, as well as the underlying constraints or opportunities for service delivery. Whilst there are many common themes, there are still enormous variations between Indigenous cultures in Australia today. We aim to provide enough background to show that service providers will encounter significant social and cultural issues. We hope that it will demonstrate to policy makers and practitioners that this knowledge can’t be simply acquired and that they will need to work in close partnership with local community mentors.

Non-aboriginal workers are often keen to have some sort of simple checklist or guide to ritual practices important to Aboriginal clients, but these will differ according to the individual circumstance. Assumptions made on the basis of any rigid set of rules can lead to mistakes. The most useful advice for a novice to any new community is to seek local guidance... Nevertheless, the preparation practitioners have for dealing with and learning from a given death can be improved. Recognition of the complex and dynamic nature of Aboriginal societies, a critical examination of ones own beliefs and values, consideration of the practical work involved and advice about the cultural mentoring process can all be valuable tools in constructing an appropriate cross cultural response... [(Fried 2000) (p236)]

3.2 Socio-economic circumstances

Many Aboriginal and Torres Strait Islander people live in very marginal social and economic conditions, with high levels of unemployment, low levels of education and literacy, poor underlying health and high death rates. The median age at death for Aboriginal and Torres Strait Islander people is 51, some 26 years

less than for non-Indigenous people, and the life expectancy gap between Indigenous and non-Indigenous people is 20 years (Ring and Brown 2002). School retention rates at Year 12 are 36% for Indigenous people compared with 73% for the total population¹ and in some regions literacy rates are extremely low².

On the other hand, many Aboriginal and Torres Strait Islander people live ordinary middle class lives. It is important not to create or apply stereotypes or make assumptions about the socio-economic conditions of clients, but there are some circumstances which will be true for many Aboriginal and Torres Strait Islander people and which will impact upon the ability of service providers to deliver appropriate services. Some of these include:

- literacy and education levels;
- high mobility;
- poor housing and overcrowding;
- high levels of domestic violence and substance misuse;
- low income levels;
- poor underlying health;
- fear and dislike of hospitals, of the health system and officials generally;
- fear and distrust of non-Indigenous people coming to their home.

It is important that the reality of the socio-economic factors affecting delivery of palliative care are acknowledged. Service providers must find ways to provide services in the contexts in which people feel comfortable, and if it is the wish of the client, to advocate to change those conditions to allow appropriate levels of care. Some of these issues are directly relevant to the capacity of Indigenous people to care for family members at home and to their willingness to access health services.

3.2.1 Housing

Many Indigenous people live in public housing. Rooms are often very small and unsuitable for hospital beds and other equipment. Dealing with public housing authorities to arrange modifications (eg. for bathrooms) can take long periods of time. Sometimes patients don't live long enough to see the modifications that have been ordered.

Aboriginal peoples' houses are not set up for palliative care. There is too much overcrowding. Many people in this town live in caravan parks – there is a severe housing shortage. There is embarrassment about inviting strangers to homes such as these and yet there is a great need for respite services for people looking after people at home. [AHW, NSW]

Extended families often live together in a house, which may be too crowded to easily provide an appropriate setting for care; yet being with family is likely to be an important issue for the client and family.

¹ Ring, I. and N. Brown (2002). 'Indigenous health: chronically inadequate responses to damning statistics'. *Medical Journal of Australia* 177((11)): 629-631.

² Learning Lessons, the independent review of Indigenous education in the Northern Territory by former Senator, Bob Collins, reported that only 4% of Year 5 Indigenous students in non-urban NT schools, and only 36% in urban schools met national reading benchmarks in 1998, and that standards were in fact deteriorating.

In the words of an AMS doctor:

Service providers do not understand that the home they are visiting is likely to be the home of an extended family and that the client or their carer may not be the dominant person in the household. Visitors need to understand that all of the lives of the people who live in the household are affected by the visit.

In many remote communities there is a serious shortage of housing stock. In many areas the fact that families must vacate a house (for substantial periods of time) when someone dies there, adds to the housing shortage and overcrowding.

Often housing is substandard and in some remote areas there is no power. There may be no refrigerator for medication and no ability to secure dangerous drugs. There may be no washing machine.

Dealing with bed sores, getting toileting and pain under control in the dirt is a difficult thing; having a bunk – commode chair and rails on the bed. There are also the practical things like running out of sheets and pillowcases and blankets and no one to wash the dirty ones. [Remote area clinic staff]

It is often a major problem for families to travel from remote places to support sick people in city hospitals, or visit family in nursing homes or aged care accommodation.

3.2.2 Capacity

Many families do not have the capacity to care for sick family members. Some people reported that the breakdown of family and cultural values mean that younger people don't take the responsibility they should, and therefore the burden of care may often fall on just one person. Access to respite care is very difficult, especially in remote locations and people find it difficult to find out how to access the carer pension. Families have commitments to work to earn money which sometimes makes caring for a sick person difficult. In Queensland we were told of one case where the palliative care client was looked after by her grandchildren outside school hours and was heavily sedated much of the time to assist with the caring.

Many families are only too well aware of their shortcomings in western eyes.

We won't ask because it is a shame job. [Queensland metropolitan community member]

Low income levels makes any extra cost a severe burden and we were often told of people going without medication to pay for other family necessities.

We were also told that some family members take advantage of sick family members and take their pension money.

3.2.3 Poor underlying health

Late diagnosis was reported as a major issue by service providers everywhere – both in cities and in remote areas. Aboriginal and Torres Strait Islander people tend not to live long after diagnosis. This has important implications for palliative care service providers who have little or no time to develop a relationship with the family before the patient passes away.

The poor health status of Indigenous people means that many people die before they develop the sorts of diseases, such as cancer, which account for 80% of non-Indigenous palliative care cases. A study of cancer (Thompson and Irvine 2001) amongst Aboriginal people in Western Australia revealed that the incidence of cancer among Aboriginal males was significantly lower than for non-Aboriginal males, while the female rate was about the same as for non-Aboriginal females. However the study showed that if Aboriginal people develop cancer they are much more likely to die of it than non-Aboriginal people, and that for every 100 cases of cancer among Aboriginal males there were 73 deaths, compared with only 47 for every 100 cases diagnosed among non-Aboriginal males. For every 100 cases of cancer diagnosed among Aboriginal females there were 52 deaths, compared with 43 deaths for every 100 cases diagnosed among non-Aboriginal females.

A recent article in the Medical Journal of Australia pointed out: *'Death rates overall for Indigenous people are three times as high as the rest of the population; diabetes death rates are eight times as high, respiratory deaths four times as high and circulatory conditions almost three times as high.'* [Ring and Brown 2002]

3.2.4 Poor community resources

Many households do not have telephones; public phones are unreliable or don't work at all. Many Aboriginal and Torres Strait Islander people do not have vehicles and live in areas where there is either no public transport or public transport is inadequate. Access to health services in many areas is poor.³

3.2.5 Literacy and education levels

Low levels of literacy and education have the potential to reduce the effectiveness of symptom management in the home. Awareness of these issues by policy makers and service providers is critical to development of communication systems that will guarantee adequate information and access to services. Low levels of education and illiteracy do not reduce families' need and right to know what is going on and what is likely to happen. Rather, it increases the need for better systems of communication. If service providers are supported by AHWs or Aboriginal liaison staff these problems may be reduced.

3.2.6 High levels of mobility

There are high levels of mobility within Aboriginal families, which may result from traditional practice, the need to attend to family business and/or from socio-economic factors. As a result, service deliverers find it difficult to provide consistent care. This can be a particular problem for bereavement care if the family has to relocate for cultural reasons and loses contact with support workers. These problems may be reduced if service providers are supported by AHWs or Aboriginal liaison staff.

Some service providers are reluctant to provide equipment under these circumstances because of a fear that they will not be able to retrieve it.

³ Bailie *et al.*

3.2.7 History of relationship between Aboriginal and Torres Strait Islander peoples and health systems

The history of dispossession of Aboriginal and Torres Strait Islander peoples and the link between the control of Aboriginal and Torres Strait Islander lives by white bureaucracies, their experience of a welfare system which removed children, and their experience of and attitude to hospitals is well documented in the literature. (Franklin and White 1991; Mobbs 1991; Reid and Lupton 1991) It is this history which led the Royal Commission into Aboriginal Deaths in Custody (RCIADIC) (Johnston 1991) to recommend:

- That Aboriginal people should be involved in the design and operation of health care facilities that are located in communities where Aboriginal people live. (Recommendation 530)
- That mainstream health care organisations involve Aboriginal people in meaningful ways in the process of assessing needs and providing health care. (Recommendation 254)
- That Aboriginal health services be sufficiently resourced to provide a broad range of services that include promotion and disease prevention, environmental improvements and better social welfare service. (Recommendation 259)

The National Aboriginal Health Strategy (NAHS 1989)⁴ was centred around self-determination and the later Commonwealth-State Health Framework Agreements maintain this underlying platform. These framework agreements seek to collaboratively support and develop health service delivery through community controlled health services and at the same time improve Aboriginal and Torres Strait Islander access to mainstream services.

The need for Aboriginal and Torres Strait Islander people to be able to access culturally appropriate health services is a fundamental issue which service providers and policy makers must act on. Mainstream service providers cannot assume that Aboriginal people will, or will be able to access palliative care services through an Indigenous health service and must make sure that their own services are appropriate and accessible, and/or that they are working in partnership with Indigenous organisations to deliver the best possible care.

3.2.8 Language

In many parts of Australia, Aboriginal and Torres Strait Islander people do not speak English or their English is not adequate for meaningful (and safe) discussions of medical or end-of-life issues. Medical and palliative care staff do not usually speak any of the relevant regional Indigenous languages at all. In areas where English is the first language of Aboriginal and Torres Strait Islander peoples, the form of English spoken and the context of the conversation may be difficult to understand for people who are not members of the community (see Eades 1988:97) and many language words may remain in use, especially for private parts of the body or intimate subjects.

Understanding medical language is difficult for well educated fluent English speakers; it is considerably more difficult if you do not speak English, if English is your second language or if your English varies in dialect from that of the speaker. Similarly English speakers should not expect to understand complex spiritual and cultural issues if they do not speak the language of the holders of those traditions. (Language barriers are discussed in more detail in Section 3.3.2 below.)

⁴ (1989). *National Aboriginal Health Strategy*. Canberra, Australian Government Publishing Service.

3.3 Some traditional issues impacting on palliative care provision

What is important about traditional practices is that hospital staff and palliative care staff ask about them. They need to ask if there is anything that people want done.” [AHW]

Policy makers and service providers should not think that they can ‘learn Aboriginal culture’. It is also important that they are not seen to be interfering or ‘sticky beaking’. They should be sensitive to needs, creating an atmosphere where people can ask for what they need and facilitating where necessary. Notwithstanding that most Indigenous people in an area may *usually* do one thing, every person is an individual and some people may want to do things differently. What is true for one person may not be true for another. Assumptions should not be made about cultural issues, which may change through time. What was true five years ago may not be true now.

Service providers need to be keenly aware that they come from a dominant social group and that their clients are members of a marginalised minority (which, especially for older people, has had a painful history and often painful experiences with the dominant group). Aboriginal and Torres Strait Islander people may be reluctant or unable to speak up. The cultural context of the service provider may blind them to cultural expressions of Aboriginal and Torres Strait Islander peoples. Good cultural awareness training programs (see Chapter 7) should assist in raising awareness of these issues.

3.3.1 Talking about death

Death is a highly sensitive issue for many Aboriginal and Torres Strait Islander people. In some places merely using the words ‘death’, ‘dying’ or ‘dead’ is highly offensive – *‘like a very bad swear word’*. End-of-life issues are often spoken of indirectly. Using the name of a deceased person should also be avoided in some communities and regions.

It is important to check with local Indigenous health workers about the appropriate ways to speak of these issues in the local area. Sometimes it will not be possible to speak about them. In one community in northern Western Australia, local indigenous people did not wish to speak with us about these issues at all and local clinic staff explained that people there would not look after people who were dying but would employ non-indigenous staff to do it. On the other hand, we found many other places where clinic staff and community representatives expected a similar response and were surprised by peoples’ willingness to discuss the issues we raised.⁵

In some areas of Western Australia it is important that the death of a person not be spoken of directly, however some community members in Perth (Noongars) expressed the view that talking about death at the time of diagnosis was quite different from talking about death after a person had passed away.

The medical profession should be more up front about the likelihood of someone dying so that people can get ready for it.

The Aboriginal Hospital Liaison Unit reinforced this view, even for people from remote areas. They say that knowing about a likely death beforehand is different to speaking about it afterwards and that knowing what is likely to happen is very important to people (see further below, *Doctors speaking about death*).

⁵ Sometimes their willingness indicated just how important (and problematical) people thought the issues were and sometimes it may have been an indication of how things are changing. Many people had personal experiences that they wanted to share.

There are no language or cultural interpretation services in Perth.

Whilst there is not the same sort of taboo about speaking about death in other areas, including NSW, Victoria and Tasmania, some parts of Queensland and in the south of South Australia and Western Australia, it is nevertheless a highly sensitive issue and many Aboriginal people use euphemisms when speaking about death. 'Passed away' is very commonly used. Other common terms used included:

- ready to go to sleep;
- finish up;
- pass on;
- ready to go.

Instead of saying 'terminal illness', many prefer to use the phrase 'not going to get better'. Prior (1997) (p140) states that the term 'terminally ill' is incongruent with the Aboriginal world view of '*life-death-life*' as a continuum.

These issues have relevance for both service providers and policy makers and impact on the preparation of written materials about palliative care.

Some families do not want the patient to be told that they have a life limiting illness in case the patient 'gives up'. In some parts of Queensland it was reported that patients often will not tell other family members of their condition: '*They are ashamed of it – they think that somehow it is their fault or the fault of their lifestyle. Sometimes they only tell their wife or husband and don't tell children till right at the end.*'

In the Torres Strait Islands approaching death is not commonly talked about. Suggesting to someone that they make a will is said to be like trying to put a curse on them. We were told of one case where a man accused his daughter of cursing him to die because she raised the question of a will and his wishes.

Reluctance to speak about an impending death makes it difficult to discuss 'living wills' covering issues of resuscitation or place of burial (see also Chapter 5, Section 5.5.8.)

Doctors speaking about death

The seriousness, the cultural variations and the complexity of these issues mean that health providers need training and the support of skilled and knowledgeable Indigenous people when speaking about death.

Doctors need to give families straight answers.

A doctor who has had many years' experience with an (Northern Territory) Aboriginal medical service believes clients need to be told the facts about their condition in the simplest terms possible. He has suggested that if one doctor uses an analogy to describe a medical condition to the client and another doctor tells it in another way there is a risk that the clients may believe they are being told different stories, which just adds to the confusion.

An Aboriginal woman in a regional population centre told how she had contacted staff at the Darwin hospital to request they notify her if there were any changes to her mother-in-law's condition. The staff rang after her mother-in-law had died and when she contacted the family in Darwin they had not yet been told. This caused serious problems between the woman and her in-laws.

An Indigenous doctor spoke about giving bad news to clients.

The hardest thing I find to do as a doctor is giving bad news. It's not a good thing giving bad news. I say you've got cancer – we've got to make sure that you are pain free and try and make you as comfy as possible and visit you regularly etc. Sometimes when you say it first up, when they first come back from the hospital they are still in denial and haven't come to grips that it is cancer. It is difficult giving that type of news – to tell it. Need to display empathy. Sometimes family comes in too – depending on the family dynamics. Helps to know the family – who is talking to whom. Sometimes the family will come in and talk to you. Empathy is the secret. Put yourself in that position and just think how you would feel.

As a general rule (and remembering that every situation is different), for most Aboriginal people it is very important that the family be informed that someone is close to passing away in enough time to ensure that final visits can be paid and the family can be prepared. If the right family members know then they can make the decision about who to inform, when (see below Section 3.3.3 Communication with the right people).

3.3.2 Language and communication

As mentioned above, in many parts of Australia, Aboriginal or Torres Strait Islander peoples do not speak English as a first language and some do not speak English at all. Similarly, health service providers rarely speak any of the local Aboriginal language(s). To attempt to deliver appropriate and sensitive health services, and palliative care services in particular, without being able to speak the language is extremely difficult. This is especially so in dealing with grief and loss.

Even when people do speak English, misunderstandings can occur. The following examples illustrate:

Story 1 (Northern Territory)

A palliative care coordinator gave an example of gross mis-communication between medical staff at the (major regional centre) hospital and the parents of a young boy from a remote community. Young boy was scheduled for leg surgery – parents were told 'don't worry we will fix it'. When he returned from surgery his leg had been amputated.

Story 2 (Northern Territory)

Another example was an elderly palliative care client who was in hospital awaiting surgery. The day before surgery the client was sent to have an x-ray. After the x-rays were taken, he was told 'okay you can go now'. The client thought this meant it was okay to leave the hospital. The hospital assumed client was being non-compliant and had absconded. Palliative Care AHW eventually found the client at home with family unaware of any problem.

Palliative care team suggested high turnover of staff at the (Regional) Hospital can mean Indigenous patients can see different people each day – each with a slightly different slant to the situation and this can cause serious misunderstanding.

Story 3 (South Australia)

An insulin dependent diabetic and her carer were at home. A visiting RDNS nurse asked the carer a question about feeding the client her breakfast. (The question was something about time and nature of the food). The question was interpreted as an insult; the reason for the question (in relation to sugar levels etc) was not explained and the carer took offence. The carer did not understand about the importance of diet and the time of eating to the management of diabetes. She thought that the nurse was accusing her of not feeding the client. There is a need for Aboriginal liaison to bridge the gaps. The RDNS staff member did not understand what the carer and client knew or didn't know and made wrong assumptions. Good communication did not happen.

Story 5 (Western Australia)

'Often the medical people won't listen.' A community member told a story of her son who had a tumour on the brain. The hospital sent him home. The family took him back to the hospital and told them he wasn't right – but the hospital ignored them *'then he collapsed and he never came to'*.

Even in New South Wales, the use of traditional language words is important, especially when speaking of intimate issues and parts of the body.

Having Aboriginal staff who can use local language words for sensitive issues (eg private body functions) is extremely important in putting people at their ease. [Manager of aged care facility with majority of Indigenous clients]

The need for people who can translate medical information clearly to Indigenous clients is critical. Sometimes this can be achieved by a medically trained Indigenous person, sometimes it will also require a language speaker. Having indigenous staff and/or budgeting for language speakers to work with staff is important.

Even in communities where everyone speaks English there is a need for medical and cultural advocacy. (Fried 2000) p113 citing (Harkins 1994) p180-1 describes

...the 'pseudo-intelligibility trap' which results when speakers of standard English and Aboriginal English communicate, and either or both parties incorrectly assume they have understood. This results in the rather common experience many of us have of talking with an Aboriginal person and subsequently realising that we have little idea what has transpired.

3.3.3 Communication with the right people

Service providers often assume that the main carer is also the main decision-maker. Aboriginal family relationships are often complex and individuals' roles and responsibilities should not be assumed. This is as true in urbanised communities as in more remote areas.

In some traditional communities there are strict rules about who can talk to whom about certain issues. Some people are in 'avoidance relationships' with other people in relation to certain matters. This point is very well illustrated in examples given by (Trugden 2000) and in the following examples given during field discussions:

An Aboriginal man was told of his terminal illness while in a major city for treatment. Culturally it was not his place then to tell the family so the local hospital arranged for someone from the Aboriginal medical service to tell the right people who could then pass on the information to the rest of the family.

and:

A service provider told of how a woman was always being asked to case management meetings to talk about the palliative care needs of her son and it was only when she eventually broke down and said 'Its not up to me and my husband to make decisions' staff realised they were talking to the 'wrong' person. It is not culturally appropriate for mother and father to make decisions.

An Aboriginal Health Worker said:

Service providers must get informed consent from appropriate family members. It is important for the right person to give consent otherwise there can be serious implications [eg payback – see below] for the person who gave consent.

Roles and relationships are different again in the Torres Strait:

When someone passes away here the news has to go to the in-laws. They are the ones to break the news to the family. The son-in-law tells the news to the other in-laws. In the past when you saw the in-law standing there you knew it was bad news. We call that murrigeth 'spirit hands'. At the tombstone ceremony all gifts are distributed to the in-laws – it is the family's way of saying thank you for carrying out all the arrangements.

Pressure is often placed on 'escorts' to give consent. A palliative care team member spoke of one escort who didn't have any authority to speak on behalf of the patient but authorised a procedure and the patient died. This had serious implications for the escort.

When patients have to go to the city only one escort will be funded and this is not usually enough to allow cultural safety. The single escort may not be able to fulfil the various roles required.

Need to have the right people present

As well as being sure to speak with family who are in an appropriate relationship to the client, medical staff should ensure that there is someone present who can speak the language of the person and can explain the medical issues. This may mean having someone like an Aboriginal or Torres Strait Islander nurse or health worker as well as an interpreter.

Doctors will tell patients to come back in a week – even if they have been discharged home several thousand kilometres away. Doctors don't think about what they are saying and don't understand the geography, and the patients think that they have to do what the doctor says.

Patients don't realise that they have a choice. In one case a patient was told to come to Perth for six months of chemotherapy treatment and then two months radiotherapy. With the advice and support of an Indigenous health professional, the patient decided that she would rather spend the next eight months at home with her young child with no treatment, than be in Perth receiving treatment with no guarantee of success and missing her young child.

Community members said ‘*it is important to involve the family in telling a patient what is in store for them and explaining about how it is now, how it is likely to be and about what sort of palliative care services would be appropriate.*’

As noted above, it is critical that service providers do not make assumptions about the roles and relationships of family members (eg carer, decision maker, advocate, ability to speak about a matter). There may be complex cultural issues involved in who takes what role when.

3.3.4 Male and female issues

In many places it is not appropriate for people of the opposite sex to deal with certain matters. Even in urban areas it may be culturally quite inappropriate for a young woman to bathe a senior man. It is not surprising that home-based services are rejected if these sorts of issues are not discovered or addressed.

3.3.5 Family and community

The importance of family, extended family and community members in interactions between Aboriginal and Torres Strait Islander people is important in understanding the nature of many Aboriginal and Torres Strait Islander households and the need for suitable visiting hours and spaces in hospitals (Prior 1997) (p141). The nature of Aboriginal families is discussed by Gray, Tromp and Houston (Gray, Trompf *et al.* 1991).

It is in the obligation of Aboriginal men and women to supply food outside the nuclear family unit that the term ‘family’ acquires a wider meaning in Aboriginal societies than would be allowed by direct application of the functions of Western nuclear families to an Aboriginal social context... it becomes increasingly clear that this wider sense of family is pervasive in Aboriginal societies. The most outstanding aspect of Aboriginal kinship systems was and in many ways still is, the existence of whole classes of people identified by an Aboriginal person as his or her ‘brothers’, ‘fathers’, ‘sisters’, ‘mother’, ‘husbands’, ‘wives’ or the various other classes of affines. These classificatory systems governed almost all social situations, including marriage. [p82]

Gray, Tromp and Houston go on to outline the practical implications for Aboriginal families of the attempted control of Aboriginal societies by the regulation of families and State.

Today Aboriginal families are in a constant state of flux as the result of these deprivations and their appallingly high mortality rate... Yet by any standards, and certainly from an Aboriginal perspective, the Aboriginal family has endured and retained a commonality across all regions of Australia.

They note the way members of extended families assume functions, duties and rights which in non-Aboriginal communities would be assumed either by biological parents or by the State or the Church. The role of family in palliative care is likely to be central.

3.3.6 Traditional medicine

In many parts of the Northern Territory, South Australia, Western Australia and Queensland, traditional healers are often called in by family. In some places (eg Perth, Darwin, Adelaide and Alice Springs) hospitals will facilitate access to traditional healers if requested. Sometimes the ALO will do it discreetly.

More often than not, however, it is a family matter and the hospital does not even know that a traditional healer has visited.

...if every thing else has failed sometimes the presence of the ngangkari pacifies them. It gives the sufferer peace of mind. The family feels that they have done everything that can be done and they feel culturally whole. Sometimes the intervention of the ngangkari brings remission.
[Senior AHW/AHLO, Adelaide]

The health service employs them because they believe they help them. They are an important part of maintaining Aboriginal people's health. Dying people use them. They are part of the daily lives of people and the management of the health of these people. I find if the ngangkari are worried about someone then I should be. I often consult after them, find out what the problem is – watch them when they consult. [Remote community doctor, Northern Territory]

For palliative care clients, people say that it is comforting to the patient and the family to have the traditional healer visit, because people know that they have tried everything. It is apparently becoming increasingly difficult to access traditional healers and if they have to be flown long distances it can become expensive. Some health services and community organisations now employ traditional healers or run traditional medicine clinics when a healer is in town.⁶

It is important that, if requested, palliative care service providers facilitate access to such healers without interference.

However we were also told that in some parts of the east coast of Australia some 'charlatans' were operating as traditional healers who had no basis for the knowledge that they claimed.
[Senior ALO]

Traditional medicine and traditional foods are used often throughout Australia. For example in New South Wales an Aboriginal health worker said:

Access to traditional remedies is important for people's peace of mind. A range of traditional medicines is used in the area, usually gathered by family members. This includes dy-berry leaf, cobra, nettles, red river gum sap, spores of tree ferns and tea tree smoke. The most important issue here is facilitation of access to these materials. Transport for family members to gather them is probably the area of greatest need.

In a town in Western Australia we also heard that people use a mixture of modern alternative medicine, with traditional medicines from several different cultural groups.

When Mum was first diagnosed I really wanted to know what it was, because sometimes they don't explain it to you properly. And some of them have got different languages – like Chinese or whatever. I had a friend who helped me look up on the internet about cancer and that and I looked up different medicines and went to a naturopath and got her, minerals and that. And that helped her a little, but we all fall back on the Wongi medicine.

And we also requested for some Northern (Kimberley mob) medicine and that was sent down. Believe it or not she did last a long time. We didn't think that she would last. She was supposed to pass on in January when she was diagnosed and she had the radiation.

⁶ See further recently completed film made by Erica Glynn called *Ngangkari*. The film was funded by the National Indigenous Documentary Fund (Series Five) and produced by P.Y. Media.

It was hard looking after her – the doctor said that I had to look after myself to look after her – physically, emotionally and spiritually. We really want to know what that disease is and if we can help them survive for a couple of months – we really want to know what is out there that we can use. Doctors say to you that they don't really want you using home remedies and that – we want to treat them our way. We use the Wongi medicine – use creams and drinks and teas and various things made from plants. [Woman who nursed her mother who had cancer]

3.3.7 Post death practices

Post death practices vary markedly from place to place and family to family. It is very important that palliative care providers and hospitals inquire beforehand if there are preparations that might need to be made.

In many areas of the east coast of Australia and in the south of South Australia and Western Australia, we were told that Aboriginal people like to spend a lot of time with the deceased person. Family and friends come long distances to visit, and generally expect to be able to visit the person where they passed away. In Queensland it is common for families to dress the deceased person and stay with them for 24-48 hours. One AMS suggested that rules should be changed so that if someone passed away in hospital the family should be able to take the person home to allow people to visit. Generally people do not want to visit people in the morgue, which would not usually have a suitable space for Aboriginal families (see Chapter 5, Section 5.4.3 for issues relating to hospital facilities). In fact, most people are very unclear about what the law says about how the bodies of deceased family members must be dealt with. This is an issue that should be researched (on a State by State basis) and written into the review of information booklets (eg *Palliative Caring at Home*) suggested in Chapter 7.

Some Torres Strait Islanders are Muslim and bury the person before sunset.

In some regions in the Northern Territory, the body will be flown from island to island so that people can pay respects. In central Australia and the north of Western Australia the place of death is stringently avoided and houses will be vacated until after Christian or traditional ceremonies take place 6-12 months later or sometimes after the first rains if this happens sooner. The house will then be smoked and repainted. In traditional communities the smoking ceremony must be conducted by a qualified 'law' man of the right group and it is a very different sort of ceremony to those conducted on the east coast. In some places practices are changing.

An Aboriginal person suggested that:

People need to start thinking about some of these things. People are dying one after another. There will be no rooms [houses] at all. Maybe after 2 or 3 days smoke it and then move back.

and:

People are emotionally full up and overflowing with so many deaths. In some areas if there is a death there is a shorter waiting period before moving back into a house than in the past; the house is done up and someone else moves back in.

Most aged care facilities and nursing homes in the Northern Territory with whom we spoke or who responded to our questionnaire support cultural practices. One reported waiting six weeks for a smoking ceremony before the room was re-used (despite a 20 person waiting list). The timing of the ceremonies

cannot be scheduled and are dependent on a range of issues and the availability of the right person to undertake the ceremony (see further discussion of these issues in Chapter 5, Section 5.4.5).

It was reported that some hospitals sometimes make it difficult for traditional practices to take place. This is sometimes due to staff turnover and new staff not knowing the 'right thing'; sometimes it is just bad attitude.

In many places on the east coast, smoking ceremonies are incorporated into funeral services and people sometimes want the place of death 'smoked'.

When the sick person is close to death or when they die, some people may begin traditional wailing, self flagellation, striking their heads and so on. Hospital staff in metropolitan hospitals often do not deal well with this situation (see further Section 5.5.3 *Upon Death*).

Even Aboriginal staff from different cultural groups are sometimes intolerant of this behaviour. In Perth we were told that traditional wailing by Aboriginal people from remote areas visiting relatives who are very ill or who have died is discouraged by the hospital and sometimes by Noongar staff.

Everyone needs cultural awareness training, even Noongars – because the Wongi way and the Kimberley mob way is different. [Community member]

When people die in hospital away from their family, people back at home may have difficulties following their cultural traditions. In South Australia we were told that currently no system or protocol has been established with the hospitals or the coroner that will allow for cultural needs. There is a need to establish a protocol regarding clothes and the body before the police or coroner become involved. One Aboriginal health unit has had great difficulty in the past accessing the clothes or body of the deceased when asked to do so by traditional people who urgently needed certain things to be done for 'sorry business' back in the community (eg the clothes or a lock of hair may need to be taken back to the community for 'sorry business').

Hospitals and hospices also need to know what it is a family wants to do, and what needs to be done. Are there special things for remote people? These things should be clear. [AHW, South Australia]

3.3.8 Blame and payback

In some communities in South Australia, the Northern Territory and Western Australia, blame for a death is often attributed to another person (rather than to the illness or event that led to their death). The person blamed will often be the last person who was with the person who died, or the last person to feed, bathe or give them a tablet. Being blamed for a death can have very serious consequences including abuse in the street, physical beating and ostracism.

Whilst it is not necessary for service providers to understand the complex religious and cultural issues involved, it is important that they are aware of these cultural issues and how they may affect delivery of service and the approach taken by the service provider.

'Blaming' has important implications for the delivery of palliative care

One old man is having a battle because of the fear of blame. No one in the family wants to feel responsible for him because of blame issues. If someone looks like being close to passing away the ambulance will be called. People won't bring that person to the clinic in their car because if they die they will get blamed but they don't want them to die in the house. [Clinic nurse]

It often means that it is difficult for local Aboriginal people to work in palliative care and in health care generally. It is also a reason for families 'pushing' family members into the hospital to 'finish up' in some regions.

Blame can be a problem especially when the death of a child occurs, and in Adelaide the Children's Hospital makes a regular practice of arranging tele-conferences with remote communities to make clear the medical causes of an illness and death, to try to explain that no one is to blame.

Palliative care workers can sometimes help families at this time. For example, in one instance a wife was afraid to stay with her dying husband because of her concerns about payback, so the palliative care team arranged for a carer to stay during this time.

3.4 Findings and implications

The diversity of Indigenous peoples and families and their social and cultural circumstances, vary from region to region and between States and Territories. This means that service delivery solutions will need to have local cultural input.

3.4.1 Socio economic contexts

Service providers and policy makers in palliative care need to understand the socio-economic realities of many Aboriginal and Torres Strait Islander consumers, and the impact of historical factors in Aboriginal and Torres Strait Islander peoples' views about health services. The importance of self-determination and the existence of culturally appropriate services, in particular those provided by ACCHS, should be acknowledged. Mainstream service providers should be sensitive to the needs of clients, modifying their service provision in consultation with local people, and try to engage with existing Aboriginal and Torres Strait Islander health providers to provide an integrated service.

3.4.2 Communication

Palliative care respects the dignity of the person who is dying, and is based on the person's needs and wishes, with attention to the specific needs of different cultural and religious groups. [extract from the definition of palliative care in the National Palliative Care Strategy (2000)].

Good communication is central to learning the person's wishes and needs. Barriers to communication include language and non-language barriers. Differing values and beliefs can create hidden difficulties. Being aware that complex relationships exist and impact on who should or should not be involved, for instance in care or decision making, are critical. Both cultural brokers and language interpreters are needed to deliver good palliative care.

3.4.3 Traditional issues

Facilitation of access to traditional medicine where requested and ensuring that protocols are in place to discover and accommodate end-of-life cultural practices should be an integral part of palliative care service delivery.

Service providers must be sure that actions taken or permissions sought will not have cultural repercussions, either for family members or for themselves. They should work with local cultural interpreters to find solutions. Whilst the issue of blame is not relevant to many people in metropolitan areas or on the east coast of Australia, in certain regions it is a serious issue which underlines the need for cultural awareness training and access to knowledgeable Aboriginal staff. It is important that practices and protocols are checked for cultural safety.

Some community members we spoke with in Perth (Noongars) believe that one reason why some medical staff are reluctant to tell the truth about life limiting illness is because they have heard stories about how some cultural groups look for someone to blame for deaths which would otherwise be ascribed to natural causes. Failure to inform people in a timely and appropriate manner about their long term prognosis creates serious problems for patients, especially where diagnosis may have been late. There is a need for research (and training) into appropriate ways to pass on bad news to Aboriginal and Torres Strait Islander clients. This is discussed further in Chapter 4.

To conclude, we reiterate a valuable point made by Ofra Freid (Fried 2000):

Recognition of the complex and dynamic nature of Aboriginal societies, a critical examination of one's own beliefs and values, consideration of the practical work involved and advice about the cultural mentoring process can all be valuable tools in constructing an appropriate cross cultural response... [p236]

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Chapter 4

Access to palliative care services



4.1 Information about rates of Indigenous access

4.1.1 Data sources

Systematic information about Aboriginal and Torres Strait Islander peoples' access to palliative care does not currently exist.

In response to the mainstream service provider questionnaire circulated, most responded that they ask a question about Indigenous status and most claimed that the question was actually asked, rather than the answer being assumed.

The interviews with palliative care service providers and Aboriginal and Torres Strait Islander health care providers, however, painted a different picture.

During interviews, we learned that while an Indigenous status question was asked somewhere in the admission or referral system, this was often 'upstream' of the actual palliative care admission and this data could not be readily accessed. Palliative care assessment forms usually do not explicitly ask the Indigenous status question. Most service providers could not access the information about how many of their clients were Indigenous because their systems did not allow it. For example, the Indigenous status question was often asked at the point of hospital admission, but the information about Indigenous status was not necessarily linked to the patient's records if they subsequently became a palliative care client.

Similarly, the Indigenous medical services interviewed did not keep records of the numbers of palliative care clients.

Many mainstream service providers interviewed indicated that although the Indigenous Status question was supposed to be asked, they believed that in many cases the answer was assumed, rather than asked by the person completing the form (where this was not the patient). This was confirmed by many Aboriginal and Torres Strait Islander people interviewed, who cited situations where they had not been asked the question.

When asked if their assessment forms ask about Indigenous status, most service providers initially answered 'yes', but when this matter was probed the reality almost invariably was that the form asks about social or cultural issues and does not explicitly ask about Indigenous status. This has significant implications for the delivery of appropriate care. As will be shown later, Aboriginal and Torres Strait Islander people are unlikely to volunteer social and cultural information to non-Indigenous strangers, yet it is critical that appropriate cultural advocates are enlisted to support the client at the earliest opportunity. This cannot happen if the clients' Indigenous status is not recognised.

4.1.2 Data about access to mainstream services

General information from the mainstream survey

As would be expected, the data from the mainstream survey shows that services in areas which have larger Aboriginal and Torres Strait Islander populations have more Indigenous clients. Most commonly, palliative care service providers which had had Indigenous clients stated there had only been one or two. Most respondents did not complete the question about the numbers of clients who were Aboriginal or Torres Strait Islander. Very few major base or regional hospitals responded to the survey. The service provider which had had more than 20 palliative care clients in the previous financial year was a hospital serving a very large Aboriginal and Torres Strait Islander population (7.6% of the total regional population)¹. The 23 Indigenous clients they had had in fact represented 8.8% of the total number of clients.

Percentage of Indigenous clients: information from survey and field interviews

The data show that in 75% of responses Aboriginal and Torres Strait Islander people are under-represented as clients in palliative care services.

Although many respondents could not access information about the number of Aboriginal and Torres Strait Islander clients they had, it was possible to extract some interesting information about access rates from:

- those that indicated they did know how many Indigenous clients they had and said it was nil, and
- those that were able to provide a percentage.

These responses (n=78) were recorded and compared with the 1996 ABS figures² on Aboriginal population. The results are graphed and shown in Appendix 3. Using the Australia Post map³ of post codes and the ABS population information, rough estimates were made of the Aboriginal population of the areas concerned.⁴ These figures are general approximations as there was no information about the catchment boundaries of the various services which responded. The ABS catchment boundaries do not coincide with postcode areas (the best data we had for the location of services).

Theoretically and in general, one should expect that the percentage of Aboriginal and Torres Strait Islander palliative care clients of a service should reflect the percentage of Aboriginal and Torres Strait Islander people in the overall population. The data show that in fact in 75% of responses Aboriginal and Torres Strait Islander people are under-represented as clients in palliative care services.

Given the burden of illness and high mortality rate in Aboriginal and Torres Strait Islander communities, one would expect an over-representation of Aboriginal people not an under-representation. Even though Aboriginal people are more likely to die of acute illnesses (or alternatively chronic illnesses that are not normally the province of palliative care, such as cardio-vascular disease), and therefore one might expect less need for palliative care, in fact Aboriginal people are more likely than others to die of all causes, including neoplasms.

¹ (1997). Population Distributions, Indigenous Australians – ABS 1996 Census Data. Canberra, Australian Bureau of Statistics.

² Ibid.

³ Official Australian Postcode Map, produced by AUSLIG 1993.

⁴ Most Aboriginal medical services believed that the Aboriginal population statistics underestimate the Indigenous population because for a number of reasons many Indigenous people do not complete the census.

In (McLennan and Maddon 1999), the standardised mortality rates for Indigenous cancer are calculated as 1.5 times for males and 1.4 times for females compared to the general population. Therefore, among those diseases where palliative care is traditionally seen as appropriate, Aboriginal people should be represented more strongly than their percentage in the population (in the case of cancers, up to one and a half times their proportion in the general population).⁵ In fact, instead of being over-represented by a factor of 1.5 they are under-represented.

4.2 Availability of services and resources

This study aimed to discover what sorts of palliative care services were available to Aboriginal and Torres Strait Islander clients. The types of services available in each state are outlined in Chapter 2, however the key issue in access to palliative care service is the availability of such services within each region.

There are many parts of Australia which have Aboriginal and Torres Strait Islander populations where there are few medical services (Bailie, Siciliano *et al.* 2002) and no palliative care services at all. Even where there are some medical services, there may be no services to assist people to stay at home. For example there are no palliative care services as such in the Torres Strait region:

People who are dying and come into hospital are placed in a 2-bed ward and families can come in and stay with them. There are no services to assist them to stay at home. [Field notes]

In other parts of Queensland:

There are no specific palliative care services provided to more remote Aboriginal communities in the region but some of the clinics and HACC services including [location name] Isolated Care are providing some support services. [Field notes Queensland Regional Area 1]

There is no specific funding for palliative care in the Anangu Pitjantjatjara Lands in central Australia. The community controlled health organisation provides services with the support of the Family and Aged Care Team and expert consultation advice, however caring for a palliative care client can be an enormous drain on resources.

Resource issues will decide whether palliative care clients can stay in the community or not. Not enough manpower. Finding extra nursing staff is one of the practical issues.
[Community nurse]

Even in areas where some palliative care services exist, there are often major gaps in the services available and the services which do exist are not integrated or coordinated. For instance, in one major remote population centre there was no home based palliative care service at all during 2002.

In Western Australia, Aboriginal peoples' access to medical services is an ongoing issue of concern. A media release issued by Warren Smith, Chairperson ATSIC Malarabah Regional Council, on 13 September 2002⁶ stated:

The WA government's plan to move specialist medical and administrative staff from Derby Regional Hospital to Broome contradicts both its commitment to improving regional services and the urgent need to improve the access to health services for Indigenous communities.

⁵ Given the age profile of Aboriginal disease, we would expect this greater proportion of Aboriginal patients to be generally younger than their non-Aboriginal counterparts. This of course does not take into account our argument in section 4.5 that more disease states should be considered as requiring palliative care for Aboriginal people than for others, on the basis that Aboriginal people are more likely than others to die as a result of their illnesses.

⁶ *Health Service Move Raises Access Barrier.*

The press release continues:

Derby is predominantly an Aboriginal town – Aboriginal people feel comfortable coming to town because they can find places to stay when visiting family and friends in hospital. Aboriginal people are more likely to make use of health services when they feel confident and comfortable in doing so.

Derby is also much better placed to service communities such as Fitzroy Crossing, Halls Creek and those along the Gibb River Road. Emergency travel to Broome will require extra time – perhaps the difference between life and death.

In the longer term, Derby needs to move towards a community-controlled health service such as those that operate in other communities with training and employment for local Indigenous people. The result would be more consistent health services, decisions made locally, an end to cultural differences and new regional employment opportunities.

This situation described in the press release is also relevant to palliative care provision because of the traditional values widely held by people in the Fitzroy Valley. It is crucial that health professionals know how to approach sensitive issues with tact, timing and appropriate use of language when explaining sickness.

Resource issues also affect people in metropolitan areas. A western Sydney palliative care coordinator said:

A major problem in access to palliative care services and to being supported in dying at home is that what is wanted is that there is a three week wait for community nurses. To be admitted as a palliative patient you have to first see a generalist community nurse to be assessed. Once you are on the list you can access the 24 hour nursing and the 24 hour phone number is the thing that most people find most useful. [Palliative care team at (H2)]

Not having access to 24 hour nursing is a particular problem for people who have been referred to palliative care late in their illness. They may have left it too late and so will end up at the hospice or hospital.

Kooris don't have the phone on and so the 24 hour service is not much help. Kooris will wait till Monday and go to the medical service. [ALO]

4.3 Referral issues

A major issue affecting the access of Aboriginal and Torres Strait Islander people to palliative care services is the failure of medical practitioners, both in the mainstream and Aboriginal health care systems, to refer Indigenous clients to palliative care. It appears that many Aboriginal and Torres Strait Islander people are not being referred to palliative care services or, if referrals occur they occur very late.

Most mainstream palliative care service providers we spoke with said that many GPs and specialists did not refer clients (both Indigenous and non-Indigenous) to palliative care services because of ignorance of the sort of services provided and disapproval of the palliative care approach.

Failure to refer to palliative care is also influenced by a number of other factors, including late diagnosis, the underlying health status of Indigenous Australians and eligibility issues.

4.3.1 Aboriginal medical services

Most of the Aboriginal medical services (ACCHS) we spoke with do not regard themselves as palliative care service providers. They usually see clients 9.00 – 5.00, five days per week and do not provide after hours services. Most do not employ community nurses.

AMS GPs will manage clients who have a terminal illness (usually without the advice of a palliative care specialist and often without the most appropriate drugs and equipment) and most do not provide home visiting services. (Some AMS doctors and many health workers do conduct visits in their own time where needed.)

In some areas there are no suitable palliative care services, however AMS GPs rarely refer clients to palliative care services even where they do exist. In this they are no different to other GPs. Generally GPs' knowledge of palliative care services is poor. We were told most AMS GPs would probably make an assumption that their clients will not want to access these services. Many believe that referral to a palliative care service means passing responsibility for the client to that service (rather than remaining a central part of an integrated service).

If referrals are made to palliative care, this is generally done very late in the client's illness because of:

- late diagnosis;
- lack of understanding about what palliative care can offer and the benefits of early referral; and
- a belief on the part of the GP that clients will not want to access palliative care services.

Referrals are often made only when the situation becomes desperate.

There are some examples where the AMS (often the health worker/s) has taken a coordinating and advocacy role, actively seeking out palliative care services and providing liaison between the AMS and the palliative care service provider.

When referrals are not made the patient often ends up in hospital and passes away there, which may not have been their preferred option had they been given a choice and received adequate support and advice.

An Aboriginal health service in a regional city in Queensland said they haven't had time or resources to pick up palliative care but would like to work in with other service providers – complement other services. It would be too exhausting on current staffing resources and service is open only Monday to Friday 8.30am-5pm, but suggested they could provide services during work hours if the hospital could pick up after hours. [Field notes Queensland Regional Area 1]

A metropolitan AMS doctor expressed the view that not only have AMSs made assumptions about whether clients would want to access palliative care services (and have assumed that they would not want referral to a mainstream service) but that many mainstream services believe that the AMS will provide services for Aboriginal clients.⁷

We received a report about one AMS doctor in Queensland who, when asked why he did not refer clients to the local palliative care service, said that because of Aboriginal peoples' feelings about death ('they accepted it readily as a part of life') they would not want 'life prolonging treatment' such as

⁷ This assumption is apparently fuelled in some cases by a belief on the part of mainstream nurses that there should not be separate health services for Kooris, but since there is, then Aboriginal people should go to the AMS and should not use mainstream services (*non-Indigenous nurse working for an AMS*).

palliative care and therefore he did not refer them. This example demonstrates the doctor's lack of understanding of the nature of palliative care and also the gross assumptions he made on behalf of Aboriginal people and Torres Strait Islanders in his care.

In short, mainstream services assume that Aboriginal clients will be looked after by the AMS, whilst the AMS assumes that clients will not want mainstream palliative care services. Fewer assumptions and more communication are clearly needed to ensure that AMSs and mainstream services work in partnership to provide continuity of care and the best service for clients.

A Queensland palliative care service suggested that some Aboriginal (and ethnic) organisations 'gate keep' on behalf of their clients and do not refer them to mainstream services, even when no equivalent service is provided by that cultural group.

4.3.2 Attitudes of GPs and specialists in the mainstream health system

Some Aboriginal and Torres Strait Islander people prefer to visit local GPs, rather than an AMS, or, in areas where there is no AMS, prefer to visit a GP rather than the hospital. A recent survey of local GPs in western Sydney conducted by an AMS found that most GPs did not know whether they had Indigenous clients or not.

Some people will not access the AMS because of local politics and because of confidentiality. Some don't like to wait – we don't have an appointment system. Recent interviews with local GPs revealed that most GPs didn't know if they had any Koori clients. [AMS]

Little is known about the behaviour of GPs and specialists in passing on bad news to Indigenous clients, however it is known that the GP or specialist who breaks bad news is a critical link in the referral process. The anecdotal evidence we collected suggests that:

- GPs and specialists lack knowledge of palliative care services and the benefits of palliative care;
- GPs and specialists may be reluctant to refer clients to palliative care services;
- GPs and specialists often assume that Aboriginal and Torres Strait Islander peoples will not want to access palliative care services;
- Referrals are made in a way that does not give the client sufficient support, such as:
 - bad news may be given in a way that cannot be 'heard' or properly understood by the client; and
 - referrals may be made without adequate explanation and with inadequate cultural support.

There is an assumption among non-Indigenous and medical people that Aboriginal families like to look after their own and they therefore leave it up to the family. They don't provide information to the clients or the family about how the family might be supported.

Many of the community members we spoke with believed that GPs would make an assumption that Aboriginal people would turn to their family for help, and that therefore they would not refer them to palliative care services. This was confirmed by mainstream service providers who assumed that one reason why they did not get many referrals was that *'Aboriginal families like to look after their own and medical practitioners leave it up to the family. They (doctors) don't provide information to the clients or the family'*.

In some remote and rural areas the role of the GP is critical in providing ongoing support to clients who require palliative care.

According to a Queensland hospital medical officer, an important issue for palliative care medical officers is how to manage patients in outlying centres. When patients return to their community, the local GP takes over and provides day-to-day management for these patients but there is still confusion about who is responsible for the patient. There are clear advantages in involving the family GP, and coordination mechanisms need to be worked out.

An advantage of people having their own GP is that they have taken care of that person all their life – know them and their family. [Queensland Regional Area 1]

In a rural centre in New South Wales we were told that GPs were reluctant to refer clients to the palliative care service and to palliative care specialists because this would mean that they had ‘failed’. Some refer, but refer *very late*, whilst some know about the services but still don’t refer clients.

In many places we were told that oncology departments were often late in referring clients to palliative care. ‘*They treat and treat and treat – when it is too late they refer.*’ [Palliative care CNC]

On the other hand, hospital-based palliative care workers in Brisbane believed that patients with an incurable disease who were treated in the general medical or surgical system rather than in oncology (which is often the case with Indigenous clients) were less likely to encounter health professionals who would refer them to palliative care services, apparently because of lack of awareness of those services and what they can offer.

Many patients are referred to Blue Care Palliative Care Service when they are in their last days of life. Up until this time the GP and family have been ‘managing’ to get by. It is an inappropriate use of the service. [Blue Care Nursing Service, Brisbane]

A major Queensland palliative care service provider stated:

... there is a great lack of knowledge of palliative care services on the part of GPs or hospitals unless they are dealing with a cancer patient. There is also a reluctance amongst GPs and families to access palliative care services because of what it means – or is thought to mean – and if GPs do mention it to families it is often not well explained.

In western Sydney a palliative care team reported that they were receiving an overall increase in the number of referrals from local GPs as a result of education initiatives, (however the AMS had not been included in these initiatives because it is not physically located within the boundary of that health district, even though its Indigenous clients generally do live within the health district concerned).

4.3.3 Contributory health status of Indigenous populations

Poor underlying health and late diagnosis of disease, especially of cancer, mean that Aboriginal people often die very soon after diagnosis and are not referred to palliative care services (or are not in a position to act on referral).

4.3.4 Dying of illnesses where palliative care is not appropriate

An Indigenous doctor in a Queensland AMS stated:

Palliative care numbers are low – we had 1200 Indigenous patients on data base and only two palliative care in past year. Heart disease is the biggest killer. They are probably dying from other things rather than cancer. Cancer is considered an old person's disease – Indigenous clients die from other things – very few Indigenous men die of prostate cancer. Most common is lung and GIT [Gastrointestinal Tract] cancer because of smoking.

A health professional at a major hospital in Brisbane suggested that Indigenous people are under-represented in palliative care because most illnesses that require palliative care are diseases of old age and Indigenous people do not live long enough to develop them.

4.3.5 Late diagnosis

Palliative care service providers and a number of AMS doctors believe that late diagnosis of terminal illness is one of the major factors in the lack of access to home-based palliative care.

Many Aboriginal people don't go anywhere for help until it is really necessary – when they are desperate and then they will turn up at a local GP. [AMS]

Screening programs that result in early detection of terminal illness (such as breast cancer) will result in more Aboriginal and Torres Strait Islander people accessing appropriate palliative care.

The Aboriginal and Islander Women's Cancer Prevention and Support service in Townsville, offers support to palliative care clients. This service believes they are now seeing more Aboriginal and Torres Strait Islander women with breast cancer because of the success of their screening program. More women are being diagnosed through the screening process whereas in the past they would have presented with 'secondaries' and breast cancer would not have been recorded.

4.3.6 Discharge planning and co-ordination

Inadequate or non-existent discharge planning results in poor referral to palliative care units or poor take up rates. In many places we visited, discharge planning to link patients to palliative care services was not done systematically and if it was done, it did not include the hospital Aboriginal liaison officer or other cultural advocate. This problem is usually worse where patients are discharged from city hospitals to return to a rural or remote area.

In a New South Wales rural area we were told:

If Aboriginal patients have received medical attention in hospital in Canberra or Sydney they may not have a regular GP in the home town and may not be referred to local services. City hospitals need better knowledge of palliative care services in the country and should make more referrals.

Even in metropolitan areas in some states there are problems; unless the palliative care team at the hospital has been involved with the client they may not be referred to appropriate home based services.

Discharge planning needs to take account of the context of the Indigenous clients, the social and cultural situation they will be going or returning to, and what pharmacy support and equipment will be available in their home or future care environment.

For clients in remote communities, discharge letters to local clinics or GPs are essential. We were told of many situations where patients had been discharged and returned to the community without the local community clinic, the AMS or the patient's GP knowing about it and as a result the clients are left to themselves without local support. Discharge letters may also be essential for clients to access funding for equipment.

Clients from remote communities needing specialist treatment have to travel to [the major regional population centre]. Clinic staff report the client is often back in the community for ages before they know the outcome of the visit to the specialist because discharge letters can take such a long time to be sent back to the community clinic. [Queensland Regional Area 2]

If a link to a palliative care service together with appropriate cultural liaison or support is not made at the time of discharge, then Aboriginal and Torres Strait Islander clients are unlikely to access palliative care services.

A number of service providers spoke of the need for the development of 'palliative care pathways' which could identify critical points where cultural advocacy should be included. In Chapter 8 some examples are given of 'hospital to home pathways' which, while not being palliative care examples, could be adapted for a palliative care situation. Both involve appropriate cultural support as a component of the planning.

4.3.7 Medical referrals

Some home based palliative care services providers take only medical referrals. This is potentially a barrier to Aboriginal people accessing these services as many avoid the health system. It is often the case that the need for palliative care is identified by an Aboriginal HACC worker or AHW rather than a medical practitioner. The various service providers should develop protocols that allow acceptance of these referrals and arrangement of appropriate assessments of such clients.

4.4 'Shame, fear and lack of knowledge': barriers to Aboriginal and Torres Strait Islander access to palliative care services

This section outlines the major barriers to Indigenous access to palliative care services (other than barriers to referral or failure to refer which are discussed above).

4.4.1 Indigenous knowledge of and understanding of palliative care

Most Aboriginal and Torres Strait Islander people do not know what palliative care is, and are not aware of the kinds of palliative care services available in their area or the medical conditions which might benefit from palliative care (a lack of understanding which is also evident in the mainstream community).

Many believe that palliative care services are always delivered in a hospital or hospice, and are unaware that palliative care services can be delivered at home and indeed that they may aim to assist people to stay at home if that is what they want. The problem here is that Aboriginal and Torres Strait Islander people feel isolated in a mainstream residential model and the family feel they will have limited access in a residential facility. They are unaware of the potential for home based care.

Most people were not aware of the kind of services provided or the environment that is offered by local hospices. In one centre on the south coast of New South Wales, the ALO from the district hospital organised a familiarisation tour for an elders' group to the newly opened hospice on another (former hospital) campus. This seemed to have been extremely successful in breaking down barriers relating to the past history of the hospital, as well as explaining what the hospice offered. It created positive 'word of mouth' in the community and since the visit the hospice has been well used by the Aboriginal community.

There are many misperceptions about palliative care. Many of those who had heard of palliative care thought that palliative care was only for cancer patients at the final stage of life. Many associate palliative care with aged care, and do not make a distinction between these kinds of services.

Lack of knowledge about palliative care and palliative care services is also an issue for Aboriginal and Torres Strait Islander health services, community controlled and otherwise. Most AMSs and other Aboriginal health services we spoke with (including doctors, managers and Aboriginal health workers) had little knowledge of palliative care services in their area and how they worked.

4.4.2 Indigenous experience of the health system

Aboriginal people have not always had good experiences of the health system and have themselves had, or have heard about, bad experiences of having strangers in the home. One regional service provider stated that some of the Aboriginal community members in the area do not access medical services at all. In order to work around this, the local Aboriginal Health Unit had begun running mobile clinics to the township twice a week – taking the medicine to the people.

Fear and avoidance of the health system mean it is unlikely that these patients would access palliative care. These fears are compounded by the failure of GPs to refer clients to palliative care services.

A senior Aboriginal health worker emphasised that many Aboriginal people don't visit doctors at all because they don't feel comfortable at the surgery ('*they don't feel it is a place for them*') and feel disempowered when visiting a doctor.

4.4.3 Lack of Aboriginal and Torres Strait Islander staff

Few mainstream palliative care services employ Indigenous people. When asked about barriers to accessing palliative care services, most Aboriginal people's first response was the lack of Aboriginal and Torres Strait Islander staff.

Aboriginal staff need to be employed in these services and especially at the front desk for first point of contact. At the [aged care facility] there are no Aboriginal staff. People need to be made welcome – it is cold walking in there. Need caring person/caring attitude/common courtesy and respect.

Families are keeping to themselves. They don't want to be a burden. Don't want anyone to go into their house. Don't want strangers coming in – white face. Don't want to have visitors – people calling in who never used to call in just because you are sick. [Queensland Regional Area 1]

This critical issue is discussed further in Chapters 5 and 6.

4.4.4 Lack of support at time of referral

Many Aboriginal and Torres Strait Islander people are unlikely to take up a referral to palliative care unless they receive culturally appropriate support at the time of referral.

Effective support would include the presence of a community or family member, or an Aboriginal health worker to check that the client/s had heard and understood the news about the sick family member, understood the implications and the likely course of the disease and knew what sort of services were available. Service providers tell us that it often takes families some time to come to terms with their situation and that the support offered at time of referral needs to be followed up. Having a 'cultural bridge' between the medical profession and the family, and between the service providers and the family is very important.

A South Australian community member commented:

There is a lot of grief and sorrow. People try to cope within their own family structure but they can't really address the needs of the person. This is partly because they are not given the information and counselling that they need. They need counselling so that they can handle the situation and go out and get the services that they need.

When the family looks after the person who is sick they feel that they are doing the right thing by the person.

They could make an informed choice if they had the right information and counselling to begin with.

It is imperative that the information and advice is given by an Aboriginal person. Palliative care service providers need to train and employ Aboriginal people to provide advice and support.

Aboriginal community members in Perth said that they and their family would rather be told as soon as possible and as clearly as possible – especially as the diagnosis is often late – and preferably with the aid of an Aboriginal health worker or Aboriginal nurse so that they have as much time as possible to get home or get in touch with family and get things organised.

4.4.5 Late diagnosis and referral

Late diagnosis and late referral has a serious impact on whether Indigenous people will access or successfully use palliative care services. A significant issue is that there is inadequate time for a palliative care team to develop a relationship with the client and the family. This generally takes longer with Aboriginal families than with other cultural groups, because of past negative experiences, and the history of suspicion of non-Indigenous services and fear of (non-Indigenous) authority. Many Aboriginal people believe that mainstream service providers will not take the time that will be needed.

Often, because of late referral, there is in fact no time and the problem is compounded in the stressful period of the terminal phase of the illness. The lack of time to develop relationships between mainstream staff and families can result in bad experiences. This is likely to have an ongoing impact on the take up of palliative care services, as people will communicate negative experiences by word of mouth.

4.4.6 The cost, or perceived cost, of palliative care

In Brisbane, Mrs [] suggested Aboriginal people won't access services if they have to pay fees and gave an example of Aboriginal people refusing Aged Care Packages because they would have to pay fees. [Field notes]

There was a strong belief among people we spoke with that palliative care services would cost money (which is often not the case). For many Aboriginal and/or Torres Strait Islander people, a 'normal' visit to the doctor is avoided because of the expense, so there is concern that home visits or nursing would involve costs that families cannot afford (see further discussion on this issue in Chapter 9).

4.4.7 Not knowing, not being told, not wanting to know, not wanting others to know

Many people we interviewed spoke of communication problems with doctors and felt doctors had not being 'straight' with them or their families. There were reports that people had not being told the true nature or their condition, or were not told in a way that enabled them to understand the implications and what it would mean.

As a result many people did not access palliative care services as early as they should have, and in some cases did not access them at all.

We also heard from some Aboriginal people who had not wanted the sick person to know they had a life limiting illness in case it made them 'give up'. These people were reluctant to access palliative care services, though some did so and their wishes regarding informing the patient were respected. This seems to be a very individual issue.

In regional South Australia, service providers believe that many clients, including Aboriginal clients, are not receiving palliative care. One reason given for this is that until recently palliative care was seen as care for a patient in the last seven days of life. This was changed to the last 30 days of life, then the last 90 days of life. The time period associated with palliative care had created a stigma as people felt that they were imposing that time-limit on their life or the life of a family member. Now these time frames have been removed in South Australia, palliative care services are receiving earlier referrals and as a result, families and patients are receiving support and counselling much earlier. In some other states, such as Queensland, time limits still apply.

Aboriginal people think differently – some people might not want to think about palliative care – because it usually means the end. They associate it with terminal care. [Senior health worker]

For some families, privacy is an important issue. Shame is often associated with illness, and having strangers come to the house would signal that something was 'going on' and privacy would be breached.

4.4.8 The physical setting of care

Many palliative care units are based within hospitals or hospices and are linked to palliative care beds located within them. This is a significant barrier to Indigenous access to palliative care due to the fear and dislike of hospitals and similar institutions amongst Aboriginal and Torres Strait Islander peoples. There are also practical problems of access (including transport and numbers of visitors) and concerns that the person who is ill will be isolated from family and community. Concerns about loss of control and the inability of family to be involved are also central.

Location of palliative care units in hospitals

People hate the hospital – there's a lack of respect from hospital staff – no courtesy. Queensland health workers are not community-based people; local people don't have faith in them. [Community member, Queensland]

The history of Aboriginal and Torres Strait Islander attitudes to hospitals is discussed in Chapter 5, Section 5.1.1.

South Australian community members said:

The services need to be provided in or from premises which Aboriginal people will feel comfortable approaching. Some of the hospices, hospitals and nursing homes are unsuitable – they are too polished up for Aboriginal people; they won't want to go in. If Aboriginal people are to approach a service they need to be able to see and feel sure that they will be welcome. Need to see an Aboriginal person, or flag or poster at least.

Travel to a hospice, nursing home or aged care facility can also be a significant practical problem for families, and families may feel a loss of control if their family member is in a nursing home or aged care facility. People in nursing homes and similar places often feel isolated from their family and culture.

Hospices seen as inappropriate places

Some Aboriginal and Torres Strait Islander peoples find some hospices very alien and unfriendly environments and would not consider going there. Building design or decor, air-conditioning, or lack of Indigenous staff may all be factors in their discomfort. Suitable spaces for large groups of people and access to outdoor spaces are very important to Aboriginal and Torres Strait Islander patients and their families, but are often not possible because of the physical design.

In some places people will not want to go to a place where other family or community members have died (though in some cases this can be managed by providing for cultural cleansing of the room or building).

Non-Indigenous services in the home

Whilst Aboriginal and Torres Strait Islander people are not aware that palliative care services can be delivered at home, in discussions about home-based services it was clear there was a general dislike of non-Indigenous people ('white strangers') coming to the home. The difficulties in delivering culturally appropriate support to Aboriginal and Torres Strait Islander families at home are discussed in Chapter 5 Section 5.4.

It is likely that a combination of fear of 'white strangers' coming to the house and a lack of positive ('good') 'word of mouth' within communities impact upon the take up rate of referral to palliative care.

4.4.9 Aboriginal and Torres Strait Islander attitudes and concerns

Community members and Aboriginal health workers repeatedly stated that 'people won't ask'. They don't like to ask for help. In relation to palliative care, even if people were aware of what services were available they would be unlikely to ask. It was suggested that if people were absolutely convinced it was their right and they would not be refused then they might ask for these services.

Many reasons were given to explain why people would be reluctant to take up a referral to palliative care services. For example, in Perth several comments were made:

There is often conflict between what the patient and or the wife or children want and what the culture dictates, and there is need for support in talking through these issues.

Many people don't like strangers coming in and if the person who is sick is male, there are issues with female nurses and care aids looking after him.

Aboriginal people don't know what services are available and they don't know the rules – often the eligibility criteria don't make sense – and people are shamed to ask – especially if they will be refused.

There is still a fear of 'authority'.

One Indigenous service provider said that some people don't mind accepting Meals on Wheels and having their yards cleaned, but they would not want housekeeping.

In one Western Australian community some members said that:

Many Aboriginal people would not be happy about mainstream service providers coming to the home because the nurses would see how messy the house was. [Western Australia, community member]

Similar views were echoed in Sydney:

Aboriginal people feel that the Community Health nurse is making judgements about the home and the family. [ALO]

Aboriginal people who see a white person knocking at the door are frightened – they think you are the police [Non-indigenous AMS community health nurse]

One AMS staff member suggested:

It is likely that some clients fear that if they go to the palliative care team then they might lose their link with the AMS – with the people they are used to. [AMS senior health worker]

4.4.10 Attitudes and beliefs of some mainstream service providers

Beliefs about the Aboriginal home environment

Service providers expect that Aboriginal houses will be overcrowded and that appointments will not be kept. It is also likely that some service providers believe that they and other mainstream service providers will not be welcome.

Staff on the palliative care team of a major Brisbane Hospital thought that Aboriginal and Torres Strait Islander people may be too embarrassed by their poverty to have strangers involved.

Some service providers are afraid to visit Aboriginal homes. The following example, while it does not deal with a palliative care case, is illustrative of the problem:

*...a man with 'diabetic foot' who should have been offered home treatment for his feet because he could not walk and had no private transport. He had to struggle on public transport to the clinic. Apparently he did not receive home treatment when he should have because the nursing service did not want to visit the home of this person. Eventually, after advocacy intervention, the appropriate service was offered at the man's home. Community members felt that the nursing service should have Aboriginal liaison staff to check that they are providing appropriate services and assist with communication.*⁸

The experience of a nurse who has done home visits in a remote town in Western Australia is that visiting Aboriginal clients in the home is difficult because:

Aboriginal people often might not want non-Aboriginal people in their home and Aboriginal people move around such a lot and live such an itinerant life that the right people are often not at home when nurses call as arranged. It is often necessary to come back several times before they will be admitted – or the whole family might have moved somewhere else either locally or gone back to another community.

Some mainstream service providers say that it would be better if the Aboriginal medical service had its own community nurses.

There are many Aboriginal families who provide care for their families at home and they don't have any support [hospital social worker – who knew this through her friends]

We received some reports of non-Indigenous service providers refusing to make home visits because of occupational health and safety issues.

Attitudes to Aboriginal families and culture

One community member told of a situation where there were many people visiting a person who was dying. They were there to honour the dying person. The Silver Chain nurse came in and said that there were too many people in the room. She was 'speaking down' to them. She did not understand the cultural importance of the visitors or why they were there.

4.5 Eligibility – non cancer clients

It was clear from our discussions with Aboriginal and Torres Strait Islander Health Services and community members that the range of conditions for which palliative care might be considered was greater than for other Australians. This is partly because Indigenous Australians frequently present with advanced and serious illness, and consequently reduced opportunities for treatment and cure. Partly it is also because Indigenous Australians often present with a number of co-morbid conditions or complications because of concurrent ill health which mean that their capacity to recover from serious illness is reduced. Illnesses which for non-Indigenous Australians may be serious but treatable, may be much more complicated for Aboriginal and Torres Strait Islander people, and lead to deteriorating health

⁸ This anecdote was related to the researchers from several different sources and on several occasions during field work in a major metropolitan centre. The fact that it was told again and again illustrates the importance of 'word of mouth' communication and that negative experiences will quickly become common knowledge in Aboriginal and Torres Strait Islander communities.

and eventual death. This situation is exacerbated in areas where there is reduced access to tertiary care including specialist medical treatment, and where the capacity and resources of primary care services are limited.

People that we spoke with during this project suggested that there are a number of diseases where Aboriginal and Torres Strait Islander patients were presented with few options for treatment and recovery, and yet which are not typically thought of as terminal illnesses. Despite the fact that the terminal nature of these condition was often recognised by health service providers, there has typically been no acknowledgement of the end of life issues faced by Aboriginal and Torres Strait Islander people suffering these conditions. One remote town GP in Western Australia said:

Aboriginal people suffer from a broader range of illness (other than just cancer) which could be classed as situations where palliation is appropriate, for example renal dialysis and chronic obstructive airways disease. Some renal units tend to hang onto renal patients until the end who possibly should be referred to palliative care specialists and of course there are a group of patients who choose not to begin dialysis – because they don't want to move to Perth when there is no space in the local renal unit. They usually end up in Perth anyway when they get sick. But some people make the decision not to move. Those on dialysis who are very sick could probably benefit from the skills of the palliative care team.

Part of the problem with some of these conditions is that they do not necessarily present with symptoms that require management as it is usually thought of in standard models of palliative care: they are not necessarily painful, and so technical aspects of palliation may not be called for. Patients may require ongoing medical management of their condition – for example, renal dialysis – but such management is not thought of as palliative even where there is a recognition that the patient will die in the short to medium term. Even when patients had finished with dialysis, either by choice or because the therapy was no longer effective for them, the kind of problems that they experience in the final weeks of their life are not classic palliative care issues such as pain, but, as one AMS doctor reported, ‘*an overloading of fluid, debility because of the inability to walk around, and an intractable itch which is hard to treat*’. Renal patients and their families are rarely referred for psycho-social support though they may well need to come to terms with end-of-life issues. Indeed, in the very common case where an Indigenous patient has a terminal but non-malignant illness, our informants talked about the difficulty of accessing palliative care funding for them because they were unlikely to die within six months of diagnosis. Even where funding is obtained, if patients live longer than six months then the funding may be withdrawn.

4.5.1 The particular problem of end-stage renal disease

Aboriginal and Torres Strait Islander peoples suffer from disproportionately high rates of renal failure, yet renal clients are generally not seen as palliative care clients. For example, in one remote part of Western Australia, the Palliative Care Service showed that palliative care numbers are relatively low in the region, yet an AMS doctor reported that end stage renal failure was reaching ‘mammoth proportions’ in the region and was expected to be a much bigger issue in the next five years. A new ten-machine dialysis unit was due to be set up there in a major regional town in October 2002 but it was suggested that it may not be able to cope with the increasing numbers of people from other parts of the region requiring dialysis, or meet the needs of Aboriginal people who have no connection the town.

For most non-Indigenous renal patients, renal dialysis is seen as a supportive therapy that maintains the patient until a suitable transplant can be arranged. For Indigenous patients, co-morbidities including non-insulin dependant diabetes mellitus, cardio-vascular disease, and hypertension mean that they are

often viewed as poor candidates for transplantation, and so renal dialysis is the final stage of therapy. There is a strong argument that unless a renal patient is scheduled for transplantation, they should be considered for palliative care, but with Aboriginal and Torres Strait Islander patients, even when active treatment ceases, they may not be referred to palliative care units.

Aboriginal health staff of one Northern Territory service suggested that clients on renal dialysis should be considered routinely for palliative care. They said that because of late diagnosis, someone can be in hospital, diagnosed and placed on dialysis within a single week, with no time to go home to talk to family and make decisions. They pointed out that dialysis patients were spending up to three days a week for five hours on dialysis. They often have other medical problems, and spend long periods – up to four hours – in hospital waiting rooms between appointments. Despite this, end stage renal patients were not usually being referred to palliative care services. The renal unit is now holding multi-disciplinary meetings and involving the social work department (where the ALO is situated) in these meetings. The workers pointed out that if renal clients were counted as palliative care clients there would be enough clients to support the employment of a palliative care Aboriginal Health Advocate.

Although many renal units with significant Aboriginal and Torres Strait Islander case loads look after their clients right up to the end, these units do not have the capacity to engage with the family in the same way that a palliative care unit would do. Families are often not sufficiently involved in management and treatment decisions, and are not involved early enough. A senior AHW expressed the view that

Aboriginal people need to be given an informed choice about whether to remain on dialysis or not. Patients generally do not have dialysis and the available choices explained to them. This needs to be done in time so that people can choose to go back home and die if that is what they want.

Domiciliary care workers, nursing staff and palliative care nurses and doctors often expressed the view that renal failure patients were not being referred to palliative care services early enough. The relationship between the renal unit and the palliative care team '*needs to be built up especially in the areas of pain control and withdrawal from treatment and ethical and end of life issues*'.

Renal patients are usually not regarded as palliative until the end and consequently families do not receive advice and counselling. Many people we spoke to said that patients and families are not adequately informed of the long term choices open to them early enough. It is often harder for Aboriginal families to make the decision to stop active treatment because they do not have good family support in the location in which renal dialysis is being administered – for example, in large regional centres, or in capital cities like Perth. It is often not appropriate for the family members escorting or accompanying the patient to make the decision or counsel the patient about withdrawal from treatment (see further Chapter 3, Section 3.3.3 Communicating with the right people). We heard stories from many of our remote informants, but particularly those in the Kimberley region of Western Australia, of people sent long distances from home for dialysis treatment who chose to come off dialysis treatment to return home to their families.

Although it was raised a number of times in our field work, access issues in relation to renal dialysis are not the subject of this study, and have been adequately canvassed in the work of other researchers, (Bennett, Manderson *et al.* 1995; Willis 1995; Preece 1997; Devitt and McMasters 1998a; Devitt and McMasters 1998b) This study is, however, concerned with the obvious palliative care needs of renal patients who decide to cease dialysis or for whom dialysis can no longer work. After cessation of dialysis, an end-stage patient usually has about two weeks to live. Trying to put palliative care into place in such a short timeframe is inappropriate, especially if some of that time will be taken up with travelling home.

Palliative care services and advice for the family and the patient need to anticipate the cessation of dialysis, and be introduced in plenty of time.

There was some indication that services are becoming more flexible about viewing renal patients as palliative care candidates, despite the fact that they are actively receiving dialysis and so categorised as having a chronic condition as opposed to a progressive terminal illness. For example, the eligibility criteria of one palliative care service in Western Australia included that patients must be medically referred with a progressive terminal illness with associated symptoms – physical, psycho-social, or spiritual. Despite this, the service has recently taken on several renal clients who are still receiving dialysis including continuous ambulatory peritoneal dialysis (CAPD). This means that these clients and their families have been able to avail themselves of the full range of palliative care services as needed.

4.5.2 Other chronic conditions where palliative care may be indicated

The same sorts of issues arise for clients with HIV/AIDS clients, patients with advanced cardio-vascular disease and some respiratory diseases. In South Australia and Western Australia, HIV/AIDS was raised as an issue. One informant said:

There is a major problem with follow-up treatment for HIV/AIDS patients who return to the regions. They cannot get confidential treatment and won't want people to know in their own community. They often won't tell people and end up with inappropriate care, sometimes in communities other than their own. [Health Worker SA]

In Adelaide, we were told that Huntington's Disease (Huntington's Chorea) is genetically present in a number of Aboriginal families, but sufferers were not connecting with palliative care services. Service providers raised the problem of eligibility criteria in relation to this disease.

In Perth a counselling service reported that many young Aboriginal people are being diagnosed with Hepatitis C and are being told that they will die. It appeared that they are not receiving adequate support at this time and are likely to present in the future as palliative care clients. Issues were also raised concerning long term illnesses that require nursing home care, and the problems that arise when there are no Indigenous specific facilities.

In the view of one service provider there was a need to raise the awareness of the medical profession about palliative care for non-cancer conditions. This informant felt that it was a matter of improving the medical profession's capacity to raise questions about palliative care, provide adequate information and to be able to assist the family to make a plan for the end stage of the disease.

4.5.3 Non compliance and eligibility for various services.

One final issue that was raised by informants was the relation between a history of compliance with medical directions (for example, compliance with medication) and eligibility for palliative care services. Some informants said that service deliverers were too concerned about making judgements about whether patients with complex needs 'deserved' the service they provided, and that service providers needed to be less judgemental and to be seen to be non-judgemental. A number of informants mentioned the case of renal patients who are often treated as 'non-compliant' when compliance is beyond the capacity of the client and family (Humphry, Weeramanthri *et al.* 2001) (see also (Preece 1997) and (Fisher 1998)).

Another example was given of a woman who was suffering from liver failure. She was very seriously ill and dying. She had been a drinker years before but had not been drinking recently and was not drinking at the time of diagnosis. Staff from the AMS acted as advocates for the woman. They were shunted backwards and forwards because the service providers believed that the woman was 'a boozer'. Her notes recorded the fact that she had been a drinker and she was treated as 'a boozer' rather than as someone who was dying and needed palliative care. The hospital palliative care unit wouldn't accept her. She was eventually found a private bed at a hospice and had a good death with her family around her, but there was much painful and costly to-ing and fro-ing and a great deal of ill-founded judgement.

4.6 Findings and implications

There is little information about or knowledge of palliative care in Aboriginal and Torres Strait Islander communities. It is likely that the most effective information strategy would be a 'word of mouth' strategy.

As a result of late referrals service providers and families don't have the time or opportunity needed to establish good relationships, which are essential to good service delivery and to 'good word of mouth' about palliative care.

When referred late, clients do not get the information they need to be able to make informed choices about how or where they wish to care or be cared for. As a result Aboriginal and/or Torres Strait Islander patients are more likely to die in hospital, which may not be their wish.

Late referrals are due not only to the underlying health conditions of Indigenous people but also to assumptions of doctors (GPs, AMS doctors and specialists) about whether Aboriginal and Torres Strait Islander clients will want to be referred to palliative care services.

If referrals are made, but are not supported by cultural advocacy, and/or the participation of Aboriginal and Torres Strait Islander staff, then they may not be taken up.

This points to the need for the following.

4.6.1 Effective information strategies (see also Chapter 7)

The following sorts of information strategies are needed:

- Among Aboriginal and Torres Strait Islander peoples there is a need to change the image of palliative care from being about 'being put in a hospice' to being about supporting families to look after their own at home;
- For doctors and AMSs there is a need to re-position palliative care so that they appreciate and understand that rather than handing over care of the patient to strangers, they could continue to be involved as a member of the palliative care team;
- For mainstream palliative care service providers there is a need to ensure that cultural awareness training takes place (including information about Aboriginal and Torres Strait Islander service providers), to equip service providers with the skills to build relationships with these groups so that they can work together to provide the best support to Aboriginal and Torres Strait Islander clients; and
- For Indigenous health and HACC workers, develop word of mouth strategies to spread information about palliative care services to those who need it. The strategy should include information, training and education for ALOs, AHWs and Aboriginal HACC workers, and should be supported by appropriate printed information for the community.

4.6.2 Discharge planning

Better discharge planning supported by cultural advocates and/or the development of palliative care pathways which can highlight key points for participation of cultural advocates is needed

4.6.3 Indigenous staff

Employment of trained Indigenous staff or the brokering in of Aboriginal and Torres Strait Islander services (see further Chapter 6 and 7) is essential.

4.6.4 Supported referrals

It is important that families be given adequate information about illness and the course of a disease, and about what palliative care can offer to support them. This information should be given by someone they know and trust rather than a stranger.

4.6.5 Relationship building

Relationships need to be developed between mainstream and Indigenous service providers, and relationships between service providers and with clients and community.

4.6.6 Better practice in ‘breaking bad news’

The way in which ‘bad news’ is delivered is critical to Indigenous peoples’ access to palliative care services. People need to be told in a way that is appropriate to their culture and in a way that will support them in making informed choices about their future options. What is appropriate will vary from place to place.

Better training for GPs and specialists in cultural awareness and in breaking ‘bad news’ is needed. Before this can be undertaken there is a need for State or regionally-based research into how ‘bad news’ is usually delivered, how it should be done, the roles of family and cultural supporters, and links between the initial or subsequent advice of diagnosis and follow up actions such as referral to palliative care. Bodies representing Indigenous health professionals such as nurses (CATSIN), doctors (AIDA), psychologists and social workers should be consulted in the development of this research.

4.6.7 Attitudes to be changed

Assumptions need to be challenged and attitudes changed. For example, an Aged Care coordinator said it used to be assumed that Aboriginal people would not wear continence pads because they would be ‘too shamed’, but as a result of sensitive discussion and education they now distribute large quantities of continence aids in the region. Attitudes of mainstream service providers, GPs and Aboriginal and Torres Strait Islander people can be influenced (see further Chapter 5).

4.6.8 Eligibility for palliative care services

Understanding of and rules about the kinds of diseases and conditions palliative care might apply to should be broadened and National Palliative Care Strategy objective 2.4, strategy 2.4.4 should be amended to include diseases such as end stage renal failure and others (see Section 4.5 above).

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Chapter 5

Planning and delivery of care



5.1 Expectations and attitudes

5.1.1 Aboriginal and Torres Strait Islander peoples' expectations and service provider attitudes

The socio-economic and cultural contexts of most Aboriginal and Torres Strait Islanders peoples was touched on in Chapter 3, which outlines a number of issues that impact specifically upon service delivery at home, including:

- literacy, and education levels;
- high mobility;
- poor housing and overcrowding;
- low income levels;
- poor underlying health; and
- fear and dislike of hospitals, the health system and officials generally.

Aboriginal and Torres Strait Islander communities are marginal communities within the dominant 'majority' community.

These issues have implications for the way service providers are perceived and for their ability to deliver services to that marginal community.

Aboriginal and Torres Strait Islander expectations

Aboriginal peoples' experience of the health system must be seen against a background of dispossession and control by white society (Franklin and White 1991; Mobbs 1991; Reid and Lupton 1991). The health system has often not been distinguished from the 'welfare' system which was responsible for the forced separation of children from their families in the past. For example, in central Australia up until 1970, the health of Aboriginal people was within the jurisdiction of the Native Affairs Branch which had wide control over Aboriginal lives (see further (Fried 2000) (p10).

Hospitals are considered to be places of death, not of healing, and have always been feared. '*We have learned from our grandmothers not to trust hospitals.*'¹

General fear and distrust of white officials also impacts upon service delivery options.

¹ Aboriginal community member in Perth. This sentiment has been expressed to members of our research team numerous times and in many locations.

Aboriginal and Torres Strait Islander peoples' fear and distrust of non-Indigenous people coming to their home was touched on in Chapter 3 and is explored further here. Aboriginal people are generally not used to having non-Aboriginal visitors. For many the only non-Aboriginal or non-family members visiting their homes in the past have been people like 'the welfare' or 'the police', and many Aboriginal people still have strong fears of outside visitors because of the long history of 'stolen children'.

Aboriginal people who see a white person knocking at the door are frightened. They think you are the police. [non-Indigenous AMS community nurse]

Aboriginal and Torres Strait Islander people expect white visitors to be bossy and judgmental. They are aware that their houses may not be 'up to standard' and are 'shamed' to allow people in.

Families are keeping to themselves. They don't want to be a burden. Don't want anyone to go into their house. Don't want strangers coming in – white face. Don't want to have visitors – people calling in who never used to call in just because you are sick. [community member, Queensland]

South Australian community members spoke of the fear of the judgmental attitudes they expected palliative care workers would have.

People are often too shamed to get help. They have too many kids or too many relatives in the house and can't keep the house clean. When non-Aboriginal people come Aboriginal people pick up the judgment straight away. Some people are just scared of white people. [community member, South Australia]

A lot of shame goes with it. Aboriginal people worry that non-Aboriginal people will look at what the house is like and will make judgments about the house and family. Aboriginal people are scarred from the history of previous interactions at home – having children stolen etc. There is a very large lack of trust. [community member, South Australia]

An Indigenous carer in Queensland said:

Some people feel shame about having white people coming in to their homes when they are ill and yet never having them to visit at any other time. People would feel they would have to rush around and clean up.

She added that over time and through familiarity with a mainstream nursing service there is a level of acceptance.

An Aboriginal and Torres Strait Islander service provider in Queensland observed that:

There are not too many Indigenous people employed in nursing services and this has a major influence.

Many Aboriginal and Torres Strait Islander people don't feel comfortable with others coming into their home – may only agree for shopping, transport and lawn mowing.

In the view of an AMS doctor:

Aboriginal people would not want strangers coming into the home. Aboriginal people will perceive non-Aboriginal service providers as being judgmental and taking an 'inspecting' attitude. They are also perceived as being bossy. It is not acceptable to be bossy in someone else's home. Service providers are also known for 'visiting at the wrong time.' If people turn up at the wrong time they may not be admitted. The house is likely to be a group house and

it may not be the prerogative of the client to have the visitor at that time if there is other family business going on. Experience from the midwife program has shown that having an AHW accompany the visit makes an enormous difference. [AMS doctor, New South Wales]

Service provider attitudes

Many mainstream service providers have never met or spoken with an Aboriginal person or a Torres Strait Islander, though they often hold preconceived ideas. Some are afraid to make approaches to Aboriginal and/or Torres Strait Islander organisations. Some have made one approach and, not being welcomed with open arms the first time, give up.

We heard stories of service providers whose attitudes and practices were supportive and non-intrusive, and who took time to build relationships with the families for whom they were caring. We also heard of service providers:

- being judgmental about the number of people present in the house;
- being concerned at the levels of hygiene possible in the house given the conditions;
- not being willing to enter Aboriginal households out of concern for personal safety.

The story of the man with ‘diabetic foot’ who did not receive appropriate treatment quoted in (Chapter 4, Section 4.4.10) illustrates the problem.

Attitudes and expectations need to be consciously considered in the planning and delivery of care to Aboriginal and Torres Strait Islander people. The need for cultural awareness training is discussed in Chapter 7.

Lack of perception of the cultural divide

Service providers need to be aware of their own prejudices and expectations. Aboriginal people claim to be able to see the judgments in the faces of the service providers, even though the service providers are not aware that they are making judgments. Fried (2000) explores in detail the barriers to cross cultural communication, including the notion of ‘cultural boundedness’ – the idea that people (especially members of a dominant culture) are so bound by their own reality that they have no awareness of the reality of others. ‘*A communication event occurs between individuals contextualised within their personal and community histories and bearing different status value and world views from one another.*’ (p116). She also argues (referencing (Reynolds 1999)) that as a result of colonial history, racism is an integral part of the fabric of Australian society, though it is rarely acknowledged (p257).

Racism... needs to be addressed with individual practitioners in a safe training and support environment, and confronted at an institutional level where it impacts on policy and practice. A culturally safe palliative practice cannot be developed and sustained unless this work is done. [Fried 2000) (p257)]

5.2 Planning and assessment

5.2.1 Discharge planning and referral

The fact that Aboriginal and Torres Strait Islander clients are not being referred to palliative care services, or are not being referred in such a way that they can act upon referrals (i.e. with adequate cultural

support and advocacy) has been discussed in Chapter 4. The referral process is critical to everything that follows.

The lack of involvement of hospital ALOs and/or the local AMS Aboriginal health workers or doctors in discharge planning for Aboriginal and Torres Strait Islander patients has also been discussed in Chapter 4.

Discharge planning has been very inadequate. One Aboriginal client with long term post-operative special dietary needs was discharged without the hospital checking the availability of the dietary supplement or the patient's ability to afford it. It is quite likely that (other) Aboriginal clients are not receiving the referrals that they should have. [AMS doctor, New South Wales]

It was suggested to us on more than one occasion that the family should be involved in discharge planning, and indeed that not only should the family be involved in decisions about the setting and nature of the care of the patient, but if the patient wishes to be cared for at home then there should be a deliberate effort to teach the family some of the key caring and nursing components while the patient is still in hospital. Inviting the family to be part of the care team prior to discharge will assist the family to understand the role that they will be taking on.

Involving the health professionals with whom the patient is comfortable, whether it is an Aboriginal health worker, their GP or a doctor from the AMS, will also be important and will assist in developing a relationship of trust with the palliative care service provider. It was suggested that discharge planning for palliative care clients should have a pathway or prescribed protocols which could include the participation points for appropriate cultural support.

5.2.2 Assessment

There was a situation where there were three ill family members (not all of them were Aboriginal) and one had Parkinson's disease. There was a context of child abuse and it was not a happy home. However there was a need for palliative care at home.

The Aboriginal liaison officer asked the domiciliary care worker and the RDNS nurse to meet her there (for the assessment) and she would do the introductions. When the nurse and domiciliary care worker turned up together they took one look at the house and family and both left together saying that they couldn't handle it. They did not even wait outside to speak with the ALO about it. They just got in their cars and took off. This was a few years ago – but there are still dysfunctional families out there. It is the reality. The ALO was in a position to assess if the environment was safe. The service providers took one look and made an assumption that it was not. The matter was eventually resolved when the ALO got a non-Aboriginal advocate to approach the service providers and they came back and an appropriate assessment was done. [South Australian care worker]

Assessment processes vary but the following describes what usually occurs.

On admission to a service or unit, service providers use the information provided by hospitals if it exists. They usually then undertake an assessment which includes establishing what the client's understanding of palliative care is and an explanation of the services available. A physical and emotional needs assessment is done and carer issues are assessed. A genealogy is drawn up. This does not specifically ask about Aboriginality, however most service providers think that the issue would come up at this time.

There is generally no involvement of Aboriginal or Torres Strait Islander liaison staff in care planning for Aboriginal and/or Torres Strait Islander palliative care clients. Sometimes each service provider will have its own assessment process and as a result questions are repeated.

There is a need for better coordination between the hospital and the palliative care service (home-based, hospital-based or hospice-based) to try to develop continuity from referral, through discharge to assessment and service delivery. Involving family and cultural advocates together with palliative care specialists as early as possible should allow better continuity than is usually experienced.

Given that Aboriginal and Torres Strait Islander people are usually not asked about their Indigenous status (see Chapter 4) and are likely to be reluctant to speak about cultural and spiritual issues with a non-Indigenous stranger, it is unlikely that the assessment process used by most service providers will come anywhere near discovering peoples' needs and wishes.

Prior (Prior 1997) claims that the way multidisciplinary assessment is handled may '*place the integrity of holistic care at risk*' if '*each member of the multidisciplinary team is focused on only one aspect of the sick person's problem*'. Further, the mix of the team may skew the emphasis. She seems to argue that a holistic approach of a palliative care team systematically examining physical, psychological, emotional and spiritual components, may be incompatible with a culturally holistic approach (involving family, community and personal issues). She advocates the inclusion of someone from the Aboriginal or Torres Strait Islander community who can address specific cultural issues.

The way people ask questions

Prior (Prior 1997) (p136) comments that systematic questioning can be perceived as authoritative and threatening.

Her study confirmed that the Aboriginal people in her study had a reluctance to share personal information with strangers. She found that people willingly disclose only details which concerned the immediate problem of the sick and were unlikely to go beyond issues of immediate needs.

Eckermann (Eckermann, Dowd *et al.* 1992) discusses good communication skills in an Indigenous health setting. In particular:

- avoiding direct questions;
- avoiding questions which invite agreement;
- using open ended questions; and
- seeking clarification.

are important communication techniques. Setting up a conversation so that it flows 'two ways' is important. The interviewer must be prepared to share information about who they are. '*We want to know who we are talking to*' we were told by community members. This didn't mean knowing from which organisation a person came, but knowing enough about the person to allow a level of trust. This level of trust may not be established on one visit alone and is likely to be hastened if an introduction is made by a trusted, mutually-known party.

Location of assessment

Where the assessment takes place may be as important as how it is undertaken. Consideration should be given to ensuring that the environment is one in which the participants feel comfortable and not

alienated or strange. If discussions take place in the home, and especially if it is a group home with more than one family present, then it may be appropriate that the discussion not take place in the sitting room or kitchen but on the verandah or outside under a tree. Service providers should be sensitive to these issues and ask the family where they want to do these things.

Aboriginal perceptions of wellbeing

Prior's study (1997) (p133) found that Aboriginal people '*placed a relatively low priority on physical illness in contrast to the importance of their community and family business. A diagnosis of life-threatening disease such as cancer, is not necessarily the person's first concern nor is it perceived as preventing them from caring [sic] out their family duties*'. The importance of other issues, such as getting home to country, as opposed to symptom control is discussed in Section 5.3 below.

Prior (1997) (p140) emphasises the need to include the social and cultural basis of illness. She recommends that practitioners use an 'explanatory' model of illness in forming assessment. Such a model guides practitioners to seek out not only the social basis of illness but also what the illness means to the person and their community.

As was suggested to us numerous times, the services of Aboriginal and Torres Strait Islander workers trained in palliative care and who bring cultural skills to the situation should be purchased in the same way as other members of the allied health team, except that their involvement should begin even earlier. Indeed, in many cases Aboriginal and Torres Strait Islander workers should be the coordinators and/or Aboriginal and Torres Strait Islander health organisations the purchasers of the palliative care and other services where their clients are involved.²

The involvement of appropriate Aboriginal and Torres Strait Islander staff as members of multidisciplinary teams and their presence and active involvement in the assessment process is critical. Conducting assessments in a culturally appropriate way (without multiple service providers asking their particular sets of questions) seems to be critical in building a relationship and in finding out what people actually need.

Involving family in the development of care plans is critical. One of the objectives of the assessment and planning meetings should be to establish what the family needs in order to be able to provide care. This should not focus only on equipment but should also consider information and coaching needs of family members (note however Section 5.4.2 below, *Identification of the right person*).

Service providers should work with local Aboriginal and Torres Strait Islander health professionals to develop appropriate assessment tools and protocols. It is not only the questions that are asked, but the manner and context in which they are asked that is important. Given the great variation in Aboriginal and Torres Strait Islander cultures, local input is essential.

5.2.3 Palliative care service provider access to cultural specialists

Most palliative care service providers have ready access to a range of specialist advisors and ancillary services. Large gaps include service provider access to Aboriginal and/or Torres Strait Islander cultural

² The education and training needs of Aboriginal and Torres Strait Islander health organisations about palliative care are addressed in Chapter 7.

advisors, liaison staff, language interpreters and Aboriginal health professionals. Palliative care service providers should make every effort to:

- identify what Aboriginal and/or Torres Strait Islander services are available in their areas (eg: AMS, State Government Indigenous Health Unit, community organisation, language and culture centres);
- develop relationships with these organisations; and
- budget for funds to broker in services where needed.

Alternatively, service providers could employ their own Aboriginal and/or Torres Strait Islander specialists. None of the major nursing services we spoke with (Blue Care, Silver Chain, RDNS, etc.) had any Aboriginal or Torres Strait Islander liaison staff working in palliative care and most had no Aboriginal or Torres Strait Islander staff at all. We understand that Blue Care in Queensland has recently employed an Indigenous Employment Officer to develop Aboriginal and Torres Strait Islander employment within the organisation.

Aboriginal and/or Torres Strait Islander service providers who are delivering some palliative care services or services to palliative care clients should make contact with mainstream palliative care service providers to help ensure that mutual clients are receiving all the services they need and are entitled to, and to establish ways of working together.

5.2.4 Appropriate roles of palliative care workers

The role taken by the palliative care service provider will depend upon what is appropriate to the local area (whether the care setting is in a remote location, whether the palliative client is also a client of the AMS, whether the GP is involved, who it has been agreed will be the co-ordinator, etc³), but it will also depend upon the attitude of the service provider. In our discussions with service providers and their clients around the country, we were struck by the range of roles that service providers took or were perceived as having.

In the area of symptom control, the different roles we heard about ranged from ‘bossy know-it-all’ to ‘humble coach’, or from ‘nurse in shining uniform bearing syringe’ to ‘willing supporter of family needs’.

An Aboriginal woman described how much her family appreciated having a palliative care person coming in to show the family how to do things for her son who had a brain tumour. She said the palliative care nurse became part of the family and they could ring her in the middle of the night to check to see whether they were doing the right thing or she would pop around and check that things were okay and share a cup of tea. [Western Australia Regional Area 1]

One palliative care service we spoke with saw their role as providing education and supporting the family so that the family could undertake the care themselves. This is the sort of approach which most of the Aboriginal and Torres Strait Islander people we spoke with would appreciate.

³ ‘A major example of breaking down barriers and building relationships between Indigenous organisations is in [2pop3] where the 2ABCultural Health Service, 2AF Health Service and the community have recently formed a partnership to provide an integrated, culturally appropriate health care model for the communities of the (major river) Valley in order to avoid duplication of services and to foster continuity of care.’ (Field notes Western Australia, remote area). See also Appendix 12 for an example of a draft regional network plan from Victoria.

5.3 Place of death

Death should not be an isolated issue – there should be community involvement – you should be surrounded by the people you love. [community member, Perth]

The desire of Aboriginal people to die in their country has been well documented (Willis 1999), (Williamson 1996). The need for people to return from a hospital to their community in time is documented further in Section 5.3.1 below.

There are two other issues about the actual place of death which will affect palliative care service delivery. In many places families, although willing to look after a dying person throughout their illness (especially if they are supported in this), do not want the person to actually die at home. This is one reason why a person will often be transferred just before death to a clinic or hospital if there is one close by. There are likely to be several cultural reasons for this. People are reluctant to be 'blamed' or held responsible for a death as traditionally they may have been if a person died in their care. A death in a house may also mean significant disruption as the family may have to vacate the house for some time.

These traditions, together with a mistrust of the health system, often create significant dilemmas for the families of palliative care clients.

During the fieldwork, community members and AHWs were interviewed about whether there was a 'right' place for someone to pass away, and if so whether there were problems in achieving this. Essentially two major issues were explored. Firstly, there is the issue of an Aboriginal or Torres Strait Islander person's desire to return to their country or their home community to die and whether (and if so, how) this can be accommodated. There is also the question of where they will pass away within that country, town or community and whether it should be at home, in the clinic, in the hospital or the hospice.

There is general and strong agreement that the place of death should be the choice of the individual and their family. Views on these issues were canvassed with those we spoke with and, not surprisingly, there was variation from place to place and individual to individual. A key issue for both urban and remote peoples is that these matters (place of death) should be discussed early enough so that people can be clear about what they want and know that it can be made to happen.

5.3.1 Issues about getting home to country

In many areas the people we interviewed expressed the view that people wanted to go home to their own country or community to die. The following anecdotal evidence was provided during this study.

- A high proportion of Aboriginal and Torres Strait Islander clients are at a terminal stage of illness when diagnosed. Medical staff in remote communities may believe they are acting in the 'best interests' of the client and evacuate them to a town hospital, when often the main concern of Aboriginal patients who have reached the terminal stage may not be the physical pain but their need to return or remain at 'home'. Sometimes remote medical staff do not feel that they can take that responsibility.
- We were told of cases where patients records had not been properly checked and people with incurable illnesses were sent to Perth for treatment. We were also told of cases where people chose to return home rather than receive treatment. For example a young woman with a young family decided to go home rather than stay in Perth for six months of radiotherapy treatment.

- Staff in one remote clinic said that [Aboriginal people] should be able to die wherever they want to die and clinic staff will support them to stay in the community if that is what they want but,

There needs to be informed consent and this is very difficult when nursing staff have no ability to speak the language. Nurses need to feel confident that the family understands that the person may be cutting off their options to living.

- People would prefer to pass away in their own country with their own family, and for Walpiri people, 'It is important that we see the passing with our own eyes'.
- People are often admitted to hospital to die and are not given any information about alternative ways of coping with this stage of life.
- People often die in Perth, away from home.

Hospitals wait too long and leave it until people are too sick to travel. It is difficult ensuring that there is informed choice at the right time. The longer they stay in Perth and the sicker they are, the more expensive it is for them to get home. If they are on a stretcher then they need a nurse escort. People prefer to go home to country die – even to a regional hospital – not to die in Perth. [hospital-based Aboriginal health professional]

- A palliative care service in the Northern Territory reported that nearly all of their clients would prefer to go home but that only 50% manage to do so. The rest die in hospital, nursing home or aged care facility in the regional centre.
- Many Aboriginal people who live in Adelaide were born at (Aboriginal community), and apparently many of them would prefer to return there to die. The general view is that there are no facilities or support services in (the community) to allow this. However upon questioning informants (service providers) further, no one actually knew what sort of services might be available at (the community). Transport to get home and to get to services when they got there would also be an issue. A story was told of a child who was dying who went home to (the community) and she died in the nearest hospital at () because no one would arrange for her to have pain relief administered at home due to fears that the drugs would be stolen. The point here is that service providers too easily assume that there is no way people can go home without exploring all the options and finding a way to make it work.

5.3.2 People wanting to die at home but ending up in hospital

In many places people reported that they and their families would prefer to die at home, but apparently few achieve that. Even where people are looked after at home throughout their illness they are likely to go to the hospital suddenly at the final stage. There may be several reasons why this occurs.

Capacity

Sometimes people do not have the capacity to care for people at home. They may not have appropriate housing, or may not have the skills or time to care for someone, especially if they have young children and/or other people (eg parents to care for). Houses are overcrowded and not well equipped to allow people to be looked after at home.

Fear of the unknown

Sometimes, because most people have never been faced with this choice and have little knowledge about it, people will choose to take the person to the hospital close to the end. Sometimes this is what the dying person wants. This is likely to be the case where people have not been referred to a palliative care service or received appropriate advice and support.

Concern for pain or not being ready to let go

Sometimes (even with good preparation) people panic and call an ambulance close to the end. They are afraid that they're not doing enough for pain management or think that the hospital could look after the person better.

Fear of spirits of the dead and/or the need to vacate the house for cleansing

In many parts of South Australia, the Northern Territory and Western Australia there are strong cultural requirements regarding ritual cleansing and/or vacating places where people have passed away and this can cause people to have to leave home. Sometimes houses are abandoned for months or years; sometimes they can be cleansed and re-occupied; sometimes they are cleansed and the family will swap with another family. Sometimes people have beliefs about spirits which may not be traditional but which will still require them to leave home.

Most State and/or Aboriginal housing authorities are sensitive to these issues and accommodate a change of property, though in more remote communities there may be very limited housing stock and this is a major problem.

Aged care facilities and nursing homes in the Northern Territory and Western Australia often rush a person to hospital if they think that they are going to die so they will not have to have rooms empty or cleansed. The death of a person in a clinic in a remote community also causes difficulties for ongoing use.

Not wanting to be in proximity – blame and payback

In some traditional communities it is common for family members to look for someone to blame for a death and to take 'payback' actions which may include physical violence toward the person blamed for the death. Often the person blamed is the person who has been caring for the sick person. Fear of payback means that family may be reluctant to keep the person with them when they are near death.

In one remote town where many people wanted to look after family members but could not have them die at home because of the need to vacate the house, and where the hospital is strongly associated with death (which makes it uncomfortable for people to use it for births or healing), the community had proposed the building of a 'care centre':

We should have a separate care centre here in town. A place put aside for people who have illnesses who know that their time is up. Not at the hospital which should be for treatment of things – separate from the hospital, a different place altogether. And a place where family can come and go. It would be a big room – really two units with some shared facilities so that the family can stay.

This centre could be used by renal clients well as cancer patients.

The care centre should have a unit for people from out of town.

Community members said they would prefer it if such a centre was just for Aboriginal people. The AMS doctor in this town supported this notion, believing that one reason for late diagnosis was that people feared the health system and the hospital so much that they avoided seeking help until the very end.

At a meeting in the Pitjantjatjara Lands on the border between South Australia and the Northern Territory, senior men and women discussed the problem of caring for people who were dying and the cultural dilemmas that arose. What they suggested was that each community should have a building – detached from but close to the main health clinic building – specifically for palliative care clients. It was also suggested that it have a similar design to the guest quarters on the Lands, which have bedrooms, a detached kitchen and ablution block and have a phone connected to the clinic for emergencies at night. The building should have room for the family to stay and to cook. People suggested that after the person had passed away the building could be ‘cleaned up’ after ‘sorry camp’ and be ready for the next person to move in.

In a relatively remote but large town in South Australia an example was given of how the cultural dilemma (and overcrowding) could be overcome. The Aboriginal housing authority provided a house for a man who needed palliative care. This meant that his family could come and care for him there, but not everyone had to live there. There was enough room for him to have a hospital bed and lock up his medication etc. After he died the house was cleansed and the family members who had been staying went home to their normal house.

There are several aged care facilities in remote communities which are being designed to take account of cultural issues (eg Oak Valley). At Wanarn community in the central desert region of Western Australia, an aged care facility was built and opened in 2002.

Our main aim in the beginning of the palliative care program was that the elderly had/have a choice to die in their own Lands, rather than being sent to Kalgoorlie nursing homes... The facility is currently only a low care facility, (due to staffing)... at first it was thought that maybe in the Aged Care Centre there could be a respite bed for palliative patients, but that could be difficult if the person was under 50 years of age, as due to the way funding works there are strict rules that only people over 50 or 55 can stay at the Aged Care Centre... there have been discussions and decisions made re the old people dying in the aged care centre, as this is very much a cultural issue. [email from palliative care coordinator]

5.3.3 Inadequacy of hospital facilities

There are three major problems with people dying in hospital:

- hospitals often do not cater well for the cultural and social needs of Aboriginal and Torres Strait Islander people and their families, both because of the physical layout and staff attitude;
- hospitals are alien places, with few if any Aboriginal or Torres Strait Islander staff and where Aboriginal and Torres Strait Islander people feel they have no control. Hospitals are associated with the government and the welfare system and are feared; and
- hospitals are generally viewed as places of death, not of healing or caring.

These issues are discussed further in Section 5.4.3, Setting of care – care in hospital.

Another issue which arose in relation to hospitals was that when palliative care patients presented at hospitals for additional pain management or because family panicked and called the ambulance,

they sometimes ended up in the emergency ward receiving inappropriate treatment rather than being referred to the palliative care unit. Most Aboriginal and Torres Strait Islander people are not good at speaking up about their needs, especially in what they perceive to be a hostile environment such as a hospital. This means that it is especially important that palliative clients are tagged in some way. One palliative care unit in western Sydney provides a registration card or booklet to people which they can take with them if they are going to hospital. This clearly identifies them as palliative care clients and indicates which service provider or doctor should be contacted. Such registration information could include directions about resuscitation preferences. Some other places are experimenting with a 'tag' or 'alert' on the hospital file in the same place that allergies are recorded.

5.3.4 Suitability of hospice facilities

Most Aboriginal and/or Torres Strait Islander people we spoke with whose family members had used hospices were generally very pleased with them. They found them and the staff a great contrast to the hospitals. Where the patient and family had visited the hospice early on in the illness for pain management or for familiarisation, this had made a big difference. Hospices that are well designed, with large enough spaces and rooms with outdoor access, and that are willing to accommodate large families and smoking ceremonies, are very much appreciated by Aboriginal and Torres Strait Islander communities. Arrangements for visiting ALOs at hospices is also very important.

Darwin hospital has been planning a new hospice and the AHW from the Northern Territory (Top End) Palliative Care Service has canvassed what should be there with the community (see Appendix 8).

The implications of place of death issues for service providers and policy makers are discussed in Section 5.9.4.

5.4 Setting of Care

5.4.1 Care in the home

'Take the time to talk – we like to know who you are.' [community member, South Australia]

Most Aboriginal and Torres Strait Islander people we spoke with told us that when someone is diagnosed with an illness from which they will not get better the family will look after that person. This is seen as the 'Aboriginal way': *'it is what we have always done, for generations'*. It is likely to be true that many Aboriginal and Torres Strait Islander families do look after their own at home without any assistance. It is also the case, however, that many Aboriginal and Torres Strait Islander people pass away in hospital when that may not be their preferred choice.

In discussions about whether palliative care was thought to be a good thing or not, most people thought that if it helped families to look after family members themselves then it was a good thing and could support what people saw as a 'traditional' way of doing things. Some serious issues were identified regarding whether that care could be appropriately delivered. The key issue was whether it was possible to receive services in the home that would not be so alien and intrusive as to make people feel they were not in control of looking after their own.

5.4.2 Planning and care issues at home

The major barriers to delivery of appropriate palliative care services in the home were identified as:

- lack of relationship;
- lack of flexibility;
- need for Aboriginal and Torres Strait Islander staff;
- lack of acceptance of social and cultural differences;
- too many strangers; and
- that the right people to discuss issues with would not be identified.

These issues and some suggestions for overcoming barriers are discussed below.

Relationships and consistency of care

One of the most commonly reported problems is that service providers are seen as strangers. Usually, no relationship exists between the service provider and the client family at the outset. There is also usually no relationship between the mainstream service provider and the Aboriginal and/or Torres Strait Islander community. This lack of relationship is exacerbated by late referrals, lack of understanding of what services can be offered, the way nursing staff are rostered, the multidisciplinary approach (multiple service providers) and cultural barriers, including lack of understanding (on the part of service providers) of what is needed and wanted.

When Aboriginal and Torres Strait Islander people who had experience of palliative care were asked what could be done to improve upon the service they had received, the most common responses were:

- have Aboriginal and Torres Strait Islander staff;
- take time – time to have a cup of tea, time to talk, time to understand;
- fewer strangers; and
- more and better information, earlier.

It takes time for people to understand what to expect, what can be offered and how they can be supported. It also takes time for palliative care providers to find out what their service can do best for the client. There is often a tendency for providers to offer services without first establishing what will be most useful to the family.

Nurses reported that an important part of developing a relationship with any palliative care client is taking the time that is needed, recognising the need to repeat information and being able to pass on information at the right time.

With Aboriginal clients who are referred very late (either because of late diagnosis or for other reasons) there is never time to pass on the information in an appropriate way or at an appropriate time. This is complicated by the living conditions where people often live in a group house, and access may be difficult. [Western Australian nurse]

Some nursing staff report having difficulty with the number of people in the household and have difficulty trying to work out who is who, especially in the short time frame.

Strategies to involve Aboriginal and Torres Strait Islander staff

The need for Aboriginal and Torres Strait Islander workers in palliative care was raised again and again. Chapter 4 discusses the need for Aboriginal and Torres Strait Islander workers to be involved in the referral process, the discharge process and in, at least, the early visits of service providers. The current role of AHWs and ALOs and other Indigenous health professionals is discussed further in Chapter 6.

Mainstream service providers that have Aboriginal and Torres Strait Islander clients need to find ways of involving Aboriginal and/or Torres Strait Islander workers, especially in home based services.

Aboriginal clients are reluctant to use the palliative care service because there is no Aboriginal face in the palliative care service. Someone [an Aboriginal person] needs to walk them through the service and they need to meet the community nurse first – before they will say yes. I often get the Aboriginal Homecare service instead of the palliative care. [ALO, New South Wales]

Some of the ways they can do this are:

- build relationships with the AHLO, Aboriginal and Torres Strait Islander HACC and CACP staff, and AMS staff;
- broker in the services of staff from these agencies to be part of the team;
- employ qualified Aboriginal and Torres Strait Islander staff in the palliative care service;
- in some places palliative care teams work closely with the AMS (if the patient is an AMS client) and this might mean that the AMS AHW acts as liaison and co-coordinator with the palliative care service, providing pain management and other advice;
- involve Aboriginal and Torres Strait Islander service providers and family members in discharge planning, care planning meetings and case management meetings; and
- work with local Aboriginal and Torres Strait Islander organisations to explore setting up and training some Aboriginal and/or Torres Strait Islander volunteers, or at least see that recruitment programs reach Aboriginal and Torres Strait Islander people and that training programs are appropriate (see further Chapter 7, Section 7.8).

Ways to build relationships with clients

'Respect the family home – don't look around.'

Advice for mainstream service providers from community members and Aboriginal and Torres Strait Islander service providers about how to build relationships with Aboriginal and Torres Strait Islander clients included:

- ensure that there is an Aboriginal or Torres Strait Islander staff member or liaison person present at the early interviews and for as long as necessary;
- be prepared to revisit and to spend time in order to find out what you can do to assist; and
- develop your credentials with the community.

Several experienced non-Indigenous service providers' staff (eg non-Indigenous doctors and nurses working for AMSs) explained the importance of establishing credentials in the community. The importance of 'word of mouth' about the service and about the individual staff members is very important. This means establishing lasting relationships with Aboriginal and Torres Strait Islander staff

and service providers, showing good faith and demonstrating sensitivity, listening skills and responsiveness.

Two ways of beginning the development of these relationships with the Aboriginal and/or Torres Strait Islander community include:

- offering in-service training; and
- taking up (or offering) work placements.

It takes considerable commitment to develop such relationships. For example, an Aboriginal Homecare coordinator in New South Wales reported that it had taken several years before the AMS and other service providers started making referrals to her service.

We [the service] had to build up our profile and had to do door-knocking to get clients for the first couple of years – despite the fact that we have Koori workers. It takes time and energy to build up trust.

An ALO from Queensland said that building up credibility with clients helps to break down barriers to access:

If people have had a positive experience with a non-Indigenous service provider they will come back to that service and look for that person even if they are there to see someone else – they feel comfortable knowing someone they know is there.

Identification of the right person within the family that the service provider can liaise with (not necessarily the carer or escort)

The complexity of Aboriginal and Torres Strait Islander family relationships was discussed in Chapter 3, Section 3.2.5. Palliative care workers providing services in the home need to be careful not to make assumptions about who the decision makers are. The primary care givers may not be the decision makers. A family spokesperson may be just that – a spokesperson only, but not a decision maker. Roles and relationships may be doubly confusing to a non-Indigenous person if the family is living in a group house. The critical thing is that assumptions about roles should not be made, though these issues should be discussed with family. Service providers should seek assistance where appropriate from trained Aboriginal and/or Torres Strait Islander colleagues.

It is quite possible that some Aboriginal and Torres Strait Islander clients will not want the local ALO or AHW involved because these people may not be in an appropriate relationship with the family. This issue also needs to be carefully checked. In the course of our study a palliative care doctor, inspired by our visit to try to do the right thing, took a new Aboriginal client along to meet with the hospital ALO (whom he himself had not met previously). It turned out that the ALO was cousin or niece of the client and was not an appropriate person to be involved.

Reducing the numbers of strangers

Another issue which people found difficult was the number of strangers involved in palliative care delivery, with each one having to make their own assessments and repeat questions. Minimising intrusion is important in all palliative care service delivery, but is doubly important for Aboriginal and Torres Strait Islander clients.

Where possible, local strategies should be developed to reduce the number of different service providers visiting a house and to make the roles of various organisations and individuals clear. This could include

preparing a list of the various service providers, providing photos of 'who is who' and drawing diagrams of the relationships between them. The most efficient way of running a service (for example, rostering staff so that clients see a different staff member each day) may present enormous difficulties for clients.

Many service providers use case management meetings as a way of coordinating care, and these can be very useful in clarifying roles and reducing the number of visitors to a house. Currently, however, case management meetings do not usually involve the AMS, the hospital ALO or another cultural representative. When palliative care services have Aboriginal and Torres Strait Islander clients they should ensure the participation of an appropriate Aboriginal and/or Torres Strait Islander service provider or community representative in the care team and case management meetings, unless that is against the wishes of the client. This person can act as a 'cultural quality reviewer'.

Provision of information

Sensitivity to the client's information needs is an important part of developing the relationship. The kinds of information which Aboriginal and Torres Strait Islander people said that they would like is summarised in Chapter 7, Section 7.2.

The need for information was one of the most common themes.

No one really knows what is involved in looking after someone with a terminal illness until they have to do it. Need information and guidance to allow the client to make a choice about their treatment, about guardianship, about where they want to die. We had a family conference, and that was good. People said they would do things but that didn't happen. We needed more information and explanation from someone. Training for family members is needed. [woman who nursed sister with HIV/AIDS]

In providing information about the condition, symptom management or what is likely to happen, it is important to recognise and to keep in mind that family members may have little education. It is possible that no one in the household may be able to read, or that English may not be the first language. Information should *always* be provided verbally, and service providers should check that it has been understood by sensitively seeking feedback. It is often necessary to repeat information on successive visits. It is also important to leave written versions of the advice and information. This enables the family to show it to others and independently check their understanding.

Being able to listen, hear and respond: communication and flexibility

The quality of the palliative care will be as good as the person is at asking and listening.
[nurse from a town in Western Australia]

Chapter 3 provided some examples of the sorts of misunderstandings that can occur in cross cultural communication.

The biggest challenge for us is to understand what they need and to make our services acceptable to them. Often the people we are dealing with are very far ahead in their illness but are still in denial because it has been left too long, and then it is too late to be able to develop what people would like. [Silver Chain nurse]

The way a service is 'normally' provided may not be appropriate. Service providers need to be prepared to modify the service to respond to cultural and socio-economic needs.

Sometimes good listening is not enough in cross cultural situations. It is very important to have assistance from someone of the same cultural group as the client, to double check that good communication is taking place. In many places it will be necessary to have an interpreter. One of the few Aboriginal health workers working in palliative care (in a region where she does not speak the local language) has reported how, having recently used the services of an interpreter, could see how essential this was to being able to explain what palliative care can offer.

Confidentiality

Many people spoke of not wanting it known that nurses were calling and said that it was very important that service providers use unmarked cars and not wear uniforms. Most service providers already aim to provide this kind of confidentiality. One nursing service had developed a system of removable decks on their cars so that they could be anonymous when visiting clients but at other times could advertise their service.

Capacity to care and respite care

Issues dealing with capacity have been covered in Chapter 3 and in Section 5.3. The need for access to respite services was raised time and again. This is especially an issue for clients who do not fit the HACC criteria and for people in remote areas where no respite services are available.

5.4.3 Care in hospital

How can the Palliative Care Unit be culturally appropriate when it is in the thick of the hospital environment – not in a friendly environment? If a family member is ill we stay right there with them. [Queensland AHW]

The context of Aboriginal and Torres Strait Islander peoples' interactions with and fears about the health system are discussed above and in Chapter 3. As noted above, hospitals are often seen as places of death rather than healing. There may also be cultural issues (avoidance) associated with the place of death (see Section 5.3).

The strength of people's feelings about hospitals should not be underestimated.

Ofra Fried (Fried 2000) (p11) refers to the relatively recent practice of having segregated hospitals in the Northern Territory. In several of the centres we visited in New South Wales there were strong recent memories of racism at hospitals. For example, an AHW now in her 50s told us that she had given up her nursing training because of racism; in another case, people still remember a separate Aboriginal-only ward in the hospital, where the cutlery and laundry were labelled 'ABO'; another hospital, where people remember mothers going to have their babies, is 'full of bad memories'. In Queensland, interviewees generally (and frequently) spoke of hospitals as hated places, staffed by people with bad attitudes.

The issues raised about hospitals were remarkably common, whether or not they were located in communities with large Aboriginal populations, or whether in cities or country areas.

The issues raised included:

- not enough (often no) Aboriginal staff except perhaps an ALO, even in areas with a relatively high Aboriginal population (for example a town where the Aboriginal population is 13% of the total has only one ALO and she is the only Aboriginal employee in the hospital). *'Just having some black faces makes a great difference'* [community member];

- ALOs are overworked, or do not work full time, or are too busy with day-to-day patient issues to get involved in palliative care issues;
- high staff turnover, especially in regional hospitals so that the number of fewer nurses have had cultural awareness training. In remote areas, the use of agency staff and foreign nurses on temporary work visas adds to the problem.

One example was a young Irish nurse who was confronted with 20 or 30 grieving Aboriginal people during her first week and did not understand about protocol and who she should speak to about the situation. This had serious repercussions for the hospital and was raised by community members on several occasions during our visit to the area.

- staff attitudes – they ‘always tell us to be quiet’:

Nursing staff need cultural understanding... Aboriginal people in [a Queensland regional centre] would rather use private GP's than go to the hospital. There are some staff with bad attitudes at the hospital. Some good ones. Local white staff have bad attitudes and bully patients. They need an Aboriginal liaison person at the front desk. Need bama⁴ in there.

Hospital staff need to have someone in there who understands language and to know:

- *about looking old people in the eye – they don't like it.*
 - *never turn your back to people*
 - *women need to work with women, men with men*
 - *who it is appropriate to talk to [community member, Queensland]*
- inadequate communication and relationship development. (Many of the issues raised above in relation to assessment and home visiting are relevant here – see also sections on communication in Chapter 3, Section 3.3.2 and 3.4.2);
 - patients' rooms are too small for visiting family and community members. Aboriginal and Torres Strait Islander community members' experience is of always having to stand in corridors;
 - air conditioning (this was reported as a problem right across northern Australia, from Western Australia to Queensland – most Aboriginal and/or Torres Strait Islander people in these regions find air conditioning uncomfortable);
 - palliative care units are either not located on the ground floor or there is no easy access to them, nor easy access to the outside – we were told that people desire access to open spaces from the palliative care area;
 - there are no suitable places where the family the whole family can come together to be with the deceased and are able to stay long enough;
 - there is no accommodation nearby for family visiting from ‘country’. At one Perth hospital, visiting family members from remote areas frequently camp in the car park;
 - people need to be able to eat food they are used to and hospitals should facilitate families bringing in appropriate food;
 - sterile and alienating environment;
 - hospitals and nursing staff are reluctant to relinquish responsibility for personal care of the patient – family members would often like to be involved;

⁴ *Bama* means Aboriginal people.

- association of hospitals with death (see Section 5.3); many suggested that palliative care beds be located in a separate building or with a separate entrance;
- some hospitals do not permit smoking ceremonies:

There is one problem. 'Smoking' a room to get rid of the dead person's spirit is not allowed at the hospital and so this means that the room where the person died is not really safe for other Aboriginal or Tiwi people. This may be one reason why Aboriginal people are often not keen to go to the hospital, because it is unsafe from spirits. Perhaps something could be done about this to accommodate the needs of Aboriginal people. [Northern Territory]

- most hospitals do not have protocols to follow to check that cultural needs can be accommodated (eg immediate access to clothing and a lock of hair for 'sorry business') especially if the person who has died is from a remote community.

We were told that things had improved in many hospitals, that attitudes were changing and staff would try to accommodate the large family groups if they could. This was especially the case with staff managing palliative care beds, however many were only too aware of how inadequate the hospitals were in accommodating the needs of Aboriginal people and of other cultural groups with extended families. In some places ALOs had organised orientation days to familiarise people in their community with the hospital and the changes that had taken place. These seemed to be effective.

One hospital has developed a special room for family groups, designed to meet the needs of the Aboriginal community, but also available for other groups (see Appendix 9). In other places we heard that requests for suitable accommodation for families had been ignored.

The trend in some States towards non-smoking (of cigarettes) on health campuses creates problems for Aboriginal families at a sensitive time, given the high proportion of Aboriginal people who smoke. Some feel that this is another way to make people feel alienated in hospitals.

The display of Aboriginal and/or Torres Strait Islander art and artefacts would be a very positive change. Community members commented favourably on hospices and nursing homes where Aboriginal art and artefacts were displayed, saying that it made them feel welcome. Prior (1997) (p131) also comments that this is an important way to demonstrate acceptance of Aboriginal and Torres Strait Islander cultures, and recommends consultation with local communities about the selection of the art works.

A list of the features Aboriginal and Torres Strait Islander people have said they would like to see incorporated into the proposed hospice in Darwin, so that it will be culturally appropriate and user friendly for Aboriginal and/or Torres Strait Islander clients, is provided at Appendix 8. The list was developed by the Aboriginal health worker of the Top End Palliative Care Service and circulated to various Aboriginal organisations, health professionals and community members throughout the Northern Territory for feedback and comment.

5.4.4 Care in a hospice

Hospices are usually separately-run facilities for symptom management, respite and terminal care which are usually physically separated from the hospital to which they are attached.

Most of the people with whom we spoke whose family had used a hospice either for pain management or for terminal care were very satisfied with the facilities and with the attitudes of staff. In general, interviewees reported that hospices did not have the same physical or attitudinal problems as hospitals. In some instances, spaces for families were not large enough or there was no private room at the time

of death, but most had rooms with suitable access to outdoor spaces and the attitudes of staff were accommodating. The biggest identified need was for a large space with its own entrance for family to remain with the deceased. In one hospice in western Sydney an Aboriginal mural and didgeridoo in the foyer made people feel at home.

Many people we spoke with thought that palliative care was synonymous with placing someone in a hospice and said that they would not want to do that, although most of these people had not been to a hospice. In two places we visited in New South Wales, the ALO from the local hospital had arranged familiarisation visits (one being a general visit for community elders and decision-makers, and another for palliative care clients) and these had made a big difference to people's attitudes towards the hospices.

We were told of a young HIV/AIDS patient who was offered a place in a hospice specifically for AIDS patients. He went and looked at it but found it too alien. He said he would not have felt comfortable there and his family would not have been comfortable visiting him there.

5.4.5 Palliative care in nursing homes and/or aged care facilities

This study has not concentrated upon palliative care of Aboriginal and Torres Strait Islander people in aged care facilities or nursing homes. Little is known about Aboriginal and Torres Strait Islander occupancy rates of these mainstream facilities.

A number of facilities are funded for Aboriginal and/or Torres Strait Islander places by the Australian Government under the Residential Care or Indigenous Flexible Funding programs, including the nursing homes and aged care facilities listed in Appendix 10.

Aboriginal and Torres Strait Islander people are generally reluctant to place family members in institutions and especially not in mainstream institutions, nor in locations remote from the person's country. However it is known that Aboriginal and Torres Strait Islander people do reside in mainstream facilities.

Some people in Indigenous-specific facilities are a long way from home, but families opt for these places because they are not mainstream... [Facility directors and family members]

While aged care and nursing homes were not the focus of this study, our initial scoping indicated that some of the Indigenous-specific facilities should be surveyed or interviewed⁵.

One of the major differences between Indigenous-specific aged care facilities and mainstream facilities is that although many of the Indigenous facilities also take non-Indigenous clients, they have very high Aboriginal and Torres Strait Islander staff numbers – usually more than 50% of staff.

In one nursing home we visited, nearly all staff, except for the nursing staff and some administrative staff, were Aboriginal. Aboriginal and Torres Strait Islander residents feel at home and comfortable where there is a high percentage of Aboriginal and/or Torres Strait Islander staff. This is in stark contrast to hospitals where there are usually no Aboriginal and/or Torres Strait Islander staff, except perhaps for an ALO.

⁵ Initial referrals to these places occurred partly because of a perception amongst some Aboriginal people that palliative care and aged care are synonymous.

Aged care facilities

The following issues were identified in relation to delivery of palliative care in aged care facilities. It is not possible to say whether these issues can be generalised to all such facilities or not. They had significance for Aboriginal and Torres Strait Islander residents.

- Aged care facilities need both male and female staff.
- In one aged care facility clients were not able to access their own doctor (informant was director of facility).
- In one instance we were told of a case in which a resident had been unable to access appropriate pain management in the aged care facility. It did not have two registered nurses and so could not administer the required drugs. We were told that the local domiciliary nurses could not attend because both they and the aged care facility were HACC funded. This very frustrating situation resulted in the resident having to leave the aged care hostel to receive the drugs she required. She went to live with relatives who were able to administer the medication. If people have chosen to live in an aged care facility they should be able to have palliative care services in what is then their home.
- In one aged care facility, residents who required palliative care generally had to be relocated to a mainstream nursing home. This was because the aged care facility did not have the staff or nursing staff to provide 24 hour care. Three palliative care clients had managed to stay 'at home' in the facility until they passed away, by a combination of assistance from family who provided 24 hour care and visits from the palliative care CNC and community health nurses. Generally this is not possible because the reason people are in such a facility is that they do not have family who can care for them.
- Lack of accommodation is a problem for Aboriginal and Torres Strait Islander people visiting family in aged care facilities. Many residents have travel a long way to get a place in an Indigenous-specific facility, which makes it difficult for visitors.
- Some aged care facilities in remote communities have apparently been designed to accommodate palliative care clients. Some are still under construction. One which is completed and occupied is viewed by community members as a place of respite – *'like a holiday home'* – and residents do not want anyone to die there, as this would mean having to vacate the centre. There would also be problems with younger palliative care clients (including end stage renal patients) being accommodated in these facilities as the funding is for people over 50 years. One new centre recently occupied by aged care clients, which was originally intended to have a section for palliative care clients, has been the focus of community discussion about the difficulties for continued occupancy should someone pass away there. This and other matters, including staffing levels, has meant that palliative care clients have not taken up occupancy.
- The layout or configuration of aged care facilities seems to be an important consideration. One family was most unhappy about the fact that their relative was in a room by herself with the door closed when she needed companionship and close monitoring. This may have resulted from the fact that she should have been in a high care facility, however some other places (hostels and nursing homes) were designed especially so that people would not be alone. Ensuring that people do not have to share with people with whom they may be in an avoidance relationship is also an important design and management issue.

Nursing homes

- In some nursing homes with Aboriginal and/or Torres Strait Islander clients, the local AMS and the local palliative care nurses work closely together to provide an integrated palliative care service.
- In one home we were told the cost of additional nursing at the time of terminal care was so great that, although the director would have preferred to buy in additional nursing and allow the person to stay until the end, she could not do so and usually sent the person to hospital to pass away.
- In several nursing homes in the Northern Territory and parts of Western Australia, Aboriginal clients judged to be at the terminal stage are removed to the local hospital as death approaches (last 3-4 days) so as to avoid the need to keep rooms vacant because of cultural requirements.
- In one nursing home, specially designed for Aboriginal clients and built from mud bricks from the major surrounding communities, a special larger room was built to accommodate a dying person and their visiting family. The room has its own access to the car park and an attached bedroom for family members. We were told this room has not been used for the purpose for which it was designed because people prefer to remain in their own room (their 'home') at this time. Use of the room would probably require additional nursing staff, and this may also have influenced whether or not it was used. This nursing home is not in a region where death necessitates vacating premises.
- One nursing home which had some palliative care clients there specifically for palliation (as well as its own clients) had no links with the local palliative care CNC and no nurses with specialised palliative care training.
- Another nursing home had a good relationship with the local palliative care team which provided symptom management advice and coordinated ancillary services as required. It also had a relationship with the local AMS whose doctors visited residents.
- In some places there did not seem to be good or regular liaison between the local AMS and Indigenous-specific care facilities.
- One AMS doctor stated that she would rather send palliative care clients to the hospital for terminal care than to the local Aboriginal nursing home because she believed that the medical care at the hospital would be better. This was despite that fact that many Aboriginal people in this town had a fear and hatred of the hospital, while in contrast, the nursing home was considered to be culturally 'comfortable'. This doctor's judgment about the level of care at the nursing home did not seem to be based on experience but on her belief in the medical system.
- A number of nursing homes and aged care facilities with Aboriginal clients provide bush tucker on the menu, facilities for outdoor cooking and living, and facilitate clients meeting their cultural obligations.
- One nursing home identified improved and more frequent access to traditional/ spiritual healers as an issue.
- Most of the nursing homes we surveyed endeavoured to comply with cultural protocols around death (see Section 5.3 Place of Death and also Chapter 3, Section 3.3.7). Some had detailed written policies (see for example Appendix 11), though many tried to avoid these situations by transferring dying people to hospital.
- There is a potential for 'western standards' to conflict with cultural desires. The importance of shared rooms is discussed above in the section on aged care hostels. The policy of one nursing home we visited (part of an international group of nursing homes) was that each patient would have a room

of their own. When asked if this was what the patients wanted, the Director replied that it was not a matter of what they wanted, the nursing home's standard was that each resident would have a room of their own and that was how it would be.

- A major issue identified by directors of nursing homes (and palliative care units at hospitals) was the lack of accommodation for families visiting from out of town. This is exacerbated by the fact that nursing homes are not usually centrally located and many visitors do not have private transport. In some places people are far from their families because there is no suitable (or Indigenous-specific) facility any closer. Some suggested that some special travel assistance to enable relatives to visit was needed.
- One nursing home identified the need for a staff position (or funding to broker in the services) of a family/cultural liaison person especially to help communicate with distant families.
- Lack of palliative care support in nursing homes means that not only may the palliative care client not be receiving the best medication, but they and their family may not be receiving the support and counselling that palliative care can offer. One nursing home director specifically identified the need for a counselling service or family liaison staff to explain what is happening to clients.
- In some places respite beds held by nursing homes are extremely important to community based palliative care services, allowing a break for families.
- A written response to our questionnaire stated:

We do and have provided care of the dying without labelling it as palliative care and within our existing minimal resources. We will continue with these practices but look forward to the result of this study to hopefully highlight to relevant bodies that our needs are different and broader than just administering medical care.

It is the extra resource of medical care that we at [name or organisation]⁶ need and of course for us to access additional resources to deliver services and support to families of the dying (i.e. accommodating immediate family members through the time of passing, advocating, coordinating and arranging travel, financial assistance, contact and whereabouts of family members, funerals, transporting back to country etc). We are able to do all these things in a sensitive and culturally relevant way, ensuring no added stress to an already stressful situation. At [name or organisation] we know the make up, factions and frictions on families and communities which is extremely important in death and dying situations... I would suggest that our organisation would look at a joint program with an appropriate mainstream unit providing medical requirements and [name or organisation] providing the social and cultural support.

Another Indigenous-specific nursing home and aged care hostel described what they thought made a good practice service:

1. *adherence to residents' and family's personal choice of care provision; includes culturally appropriate care and traditional care methods where possible;*
2. *adequate pain management – maintain comfort;*

⁶ This nursing home received 'flexible cashed out model' funding (15 high level and 10 low beds), mid-range subsidy cashed out on a monthly basis. This nursing home found it very difficult to cover the costs of additional nursing for terminal care and had had to send patients to hospital because they would not have been able to provide the level of care needed despite their high care beds. They wanted to be able to buy in palliative care services as needed.

3. *liaison with palliative care nurses, MO and allied health professions;*
4. *access to spiritual/ traditional guidance; and*
5. *training for staff specific to palliative care, where required.*

In many places (eg western Sydney and Perth) there appear to be no Indigenous-specific aged care or nursing homes.

We do not have any information about how mainstream nursing homes or aged care facilities accommodate the needs of Aboriginal and/or Torres Strait Islander clients except in some remote areas where these facilities have a high number of Aboriginal clients. In one area visited in Queensland there were no Aboriginal staff in the local aged care facility despite the fact that it had a large number of Aboriginal residents. The aged care worker from the local Aboriginal and Torres Strait Islander corporation visits this facility and takes people out to the family for the day. We were told *'it is obvious how isolated the Aboriginal and Torres Strait Islander residents feel because whenever an Indigenous person visits, residents would show immediate interest and wave and call out.'* [aged care worker]

A hostel in Perth accommodates remote area renal dialysis patients who must reside in Perth to visit the hospital for regular dialysis. It does not have the capacity to accommodate all renal patients (see Section 5.4.6, Medically supported hostels below).

The implications of the findings about aged care and nursing homes are discussed below at section 5.9.4.

5.4.6 Medically supported hostels

In centres such as Alice Springs and Perth there is a need for hostels that are designed to cater for the needs of palliative care clients and others who are very ill and in town for medical appointments.

In central Australia people talked about the need for a hostel located close to the Alice Springs Hospital, specifically for palliative care clients from remote communities who are in town for follow up appointments or travelling to or from Adelaide for treatment. The existing hostel is considered inappropriate for 'really sick people' and very restrictive, allowing only one hour for breakfast, lunch at 11.00 am and dinner between 4.00 and 5.00 pm, when people are often still at appointments.

The same issue was identified in Perth and Cairns, and such a hostel is probably needed in Adelaide as well. There are several such hostels in existence, though not specifically for palliative care clients. One hostel in Perth⁷ specialises in housing remote renal patients who are in town for ongoing dialysis. This hostel is always full and cannot handle the number of dialysis clients who come to Perth. In Cairns a hostel caters for pregnant women who have come to town to await the birth of their babies⁸ and has taken in very sick women if needed. These hostels provide health worker support, some health education and assist with transport to medical appointments. Similar hostels which specialise in short term stays for palliative clients who are in town for symptom management may be needed in a number of locations.

⁷ Elizabeth Hansen Autumn Centre.

⁸ Mookai Rosie-Bi-Bayan.

5.4.7 Palliative care for itinerant people

There are many Aboriginal and Torres Strait Islander people who do not have a house or home who may be termed ‘itinerant’ or ‘homeless’⁹. These people often live in city parks and include people who need palliative care and symptom management.

AHWs told us of their frustrations in trying to obtain any services for these people. In one regional centre in Queensland the palliative care unit and local Diversional Centre have begun discussions about ways of taking palliative care to the homeless population.

Local palliative care service providers should work with AMSs and other Aboriginal and/or Torres Strait Islander service providers and appropriate funding agencies to develop strategies to allow delivery of services to these people in the setting of their choice.

5.4.8 Palliative care in gaol

It was beyond the scope of this study to investigate palliative care in gaol, however, given the high number of Aboriginal and Torres Strait Islander people in Australian correctional institutions, and the sensitivities surrounding place of death, the question of the kinds and availability of palliative care services in prisons is clearly an important area for inmates and their families. Our data base search did not reveal this as an issue addressed by the Royal Commission Into Aboriginal Deaths In Custody (RCIADIC). Advice from Western Australia (AMS) was that if Aboriginal prisoners are diagnosed with a life limiting illness their sentence is usually commuted and they are released. This had not been confirmed.

5.5 Counselling and bereavement care

5.5.1 Counselling and bereavement care as part of palliative care services

Mainstream services

Nearly every palliative care service includes some component of counselling and bereavement care. Counselling (for the patient or family members) may occur at any time from referral onwards and varies from informal counselling by nursing staff or trained volunteers, to formal referrals to counsellors and psychologists who may be part of the palliative care team or may be an ancillary service.

Bereavement services range from those which conduct formal risk analysis followed by tailored referrals to counsellors where necessary, to fairly uniform systems of follow-up including phone calls and cards. A typical bereavement process will include a phone call a week after the funeral (usually by the team member who has had most to do with the family) and then another phone call at about six weeks. These phone calls usually offer the option for additional counselling if requested. Some programs also follow up at three and six months with phone calls, and many palliative care services hold six monthly or annual memorial services to which families are invited. Some palliative care services send a card at the first anniversary of the death.

⁹ They do not necessarily regard themselves as homeless but do not live in a conventional house and may choose to reside in a city park.

Much informal counselling is provided by trained volunteers or nurses who offer 'a listening ear'. These workers may do no more than chat with patients or family members or provide a break for them. None of the volunteer programs had attempted to recruit Aboriginal or Torres Strait Islander members. Aboriginal health workers and Aboriginal or Torres Strait Islander HACC workers provide a similar service to Aboriginal and Torres Strait Islander clients but this is usually informal and not coordinated with palliative care services.

Most palliative care services do not ask about the Indigenous status of the family of patients although some services are now formally admitting family members as clients and would then ask the question of them.

Many palliative care services are moving away from a standard bereavement counselling model (for example, programmed phone calls and cards) to conducting individual risk assessment followed by more tailored approaches where needed. The following example, drafted by the Mid North Coast Palliative Care Service in New South Wales (apparently based on the work of Mal McKissock¹⁰) identifies the following risk categories:

- death of a child;
- sudden death;
- trauma;
- ambivalence in the relationship;
- pre-existing psychopathology (including unresolved losses, alcohol and drug dependence, history of depression, personality disorder);
- concurrent crisis;
- centrality;
- perceived preventability;
- decreased (or lack of) role diversity;
- decreased (or absence of) social support;
- lack of reality; and
- overly prolonged dying.

Aboriginal and Torres Strait Islander bereavement services

Most AMSs do not have any formal process for managing bereavement, though some provide assistance with funerals or provide advocacy roles in dealing with issues surrounding death (such as making claims from Centrelink). Aboriginal health workers often provide informal and unpaid counselling which involves being available to talk with a family.

Mainstream counsellors tend to avoid Aboriginal clients and put it on untrained Aboriginal workers. There is a need to recognise the role of Aboriginal health workers in providing counselling. Training for health workers needs to be hands on – on the job. Aboriginal health workers and Aboriginal liaison staff carry a large burden – providing informal counselling and support with no training, support, or debriefing. [AMS health worker, South Australia]

¹⁰ see for example Mc Kissock, D. and M. Mc Kissock (1998). *Bereavement Counseling, Guidelines for Practitioners*, Bereavement C.A.R.E. Centre, Terrigal NSW.

There are few Indigenous-specific counselling services in existence, although there are some emotional and social well-being services associated with AMSs. Where these exist, community members we interviewed identified problems in using these services for bereavement counselling:

- The emphasis of these services tends to be on family (violence) counselling or substance misuse;
- Many of the staff in these centres are not qualified counsellors or are not qualified in grief and loss counselling; and
- There are perceived issues of confidentiality, especially where these services are housed in a general health clinic where ‘*everyone knows your business*’.

Most people we spoke with, including AMS staff, did not associate these services with bereavement counselling.

This study did not focus on emotional and social well-being services, although we spoke with some staff from these centres. Several of the AMSs we visited indicated problems with recruiting and retaining qualified staff. It was clear that the issues that are the focus of emotional and social well-being services are very difficult areas, and AMSs face difficulties in keeping up with the demand for trained counsellors and other appropriate services. Although grief and loss is acknowledged as a common underlying issue, most people who use emotional and social well-being services present with drug and alcohol or family violence issues as the more immediate problems.

There are some exceptions to this. Wuchopperan Aboriginal Medical Centre in Cairns is said to provide clinical, cultural and carer support to palliative care clients as well as bereavement and grief counselling through their Social Health team.

Two projects have been funded recently to look specifically at Aboriginal grief and loss issues: one in Victoria, managed by VACCHO; and one in New South Wales, managed by New England Community Health. Both projects are in their early stages and have not yet generated publicly available information.

5.5.2 Aboriginal and Torres Strait Islander people’s use of and need for bereavement services

When we grieve extended family comes together – talking, laughing, crying. It is important for people to have the option – a lot of us don’t look for someone else. We deal with it in our own way. I wouldn’t go to a counsellor. [community member, Queensland]

Murris like to talk and laugh!

The indications from our data are that Aboriginal and Torres Strait Islander people do not take advantage of counselling, even where these are offered as part of the palliative care bereavement service. Several reasons were offered for this, the most common being

It [counselling] is not the Aboriginal way. The family deals with it.

Most people we spoke with said they would not use the local AMS emotional and social well-being service for grief and loss counselling. They thought that these services were not resourced to provide an adequate professional grief and loss service. Many also identified a number of difficulties in maintaining privacy in small communities that pose significant barriers to providing a confidential service. The privacy issue is compounded by the fact that many people felt that there was stigma attached to going to a counsellor for many community members. As one person interviewed put it,

You only go to the counsellor if you are mad or bad.

AMS staff we spoke with confirmed that there was a perception that emotional and social well being services had a stigma attached and that there was a need to change community attitudes to mental health problems, including grief and loss.

A significant number of Aboriginal people we interviewed said that they thought that there should be trained and qualified Aboriginal and Torres Strait Islander grief and loss counsellors available. Some thought these should possibly be separate from the AMS. Some mainstream service providers we interviewed also indicated that at the request of Aboriginal and/or Torres Strait Islander clients, they had made successful referrals to mainstream counsellors where there was a special need. They had had considerable difficulties finding appropriate counsellors in the absence of Aboriginal or Torres Strait Islander specific counselling services.¹¹

In the absence of trained bereavement counsellors, many AHWs are put in the position of providing counselling and support services for which they have no training. This is true even for palliative care services which do not employ Aboriginal workers. For example, one north Queensland palliative care service involves an AHW from the local Community Health Centre in the care of their Aboriginal and/or Torres Strait Islander clients, including a 27 year old Indigenous woman client with two young daughters who presented with advanced symptoms of cancer. She received counselling from an AHW soon after presentation, and this has been ongoing.

The burden of grief for bereaved Aboriginal and Torres Strait Islander clients

What is noticeable about the risk assessment model described earlier in this chapter is the likelihood that nearly any Aboriginal or Torres Strait Islander client would be assessed as high risk because of a burden of unresolved losses, current crisis and other risk factors. Unresolved losses are likely to include not only other recent deaths in the family but other unresolved losses stemming from invasion and stolen generation issues¹². This underlines the need for action to provide better services for Aboriginal and Torres Strait Islander clients.

Close relatives and parents pass away and there is no opportunity to deal with it before someone else passes away and there are so many unanswered questions. [community member, Western Australia]

Drink, depression, low self esteem follow from the constant death rates. Unresolved grief underlies many of the health issues. This is especially so for depression and psychotic illnesses which result from marijuana use which results from unresolved grief. [AMS doctor, Western Australia]

Grief and loss counselling is needed where there are multiple bereavements, no jobs and no self esteem – leads to anger and frustration and to drink and drugs. [AHW]

¹¹ The only Indigenous services we identified (part from those associated with AMSs were Galang Place in Brisbane, Rosemary Wanganeen's *The Sacred Site Within Healing Centre* in Adelaide and a centre called Yorgum in Perth. Galang Place has qualified staff but does not focus on bereavement care.

¹² A number of grief and loss programs which have been developed incorporate these sorts of losses, including loss of cultural identity, into their programs, eg Rumbalara Medical Service in Victoria list seven stages of grief (The Dreaming, Invasion, Genocide, Protection, Assimilation, Self-determination and Reconciliation); see also processes used by Rosemary Wanganeen (Wanganeen, R. 'Self Healing and Spiritual Reconnection' *Aboriginal and Islander Health Worker Journal* 18(2).)

A counsellor working with Aboriginal clients said:

No clients don't have grief issues. All the clients we see have an unresolved burden of grief. This comes from recent deaths, from traumatic deaths, from loss and abandonment and from grief of loss of culture and identity. Other people give great support at the time of death but it is 'closed down grief'. [counsellor, Western Australia]

Because of this there is not only a need for trained Aboriginal counsellors but also a need for research aimed at developing effective treatment programs for Aboriginal clients.

5.5.3 How Aboriginal and Torres Strait Islander peoples deal with grief¹³

Most people we spoke with believed that the family would provide support and that funerals were an integral part of the grieving process.

People are very open about grief – they try to share and support one another. We prefer to see people turn up [to funerals] and we like flowers and all of that.” The group believed that the family would provide support. [field notes, community discussion, Western Australia]

The importance of family being present and involved before and after death and at the funeral was stressed over and over again, although we recognised a number of significant regional cultural differences in the way this was done.

Immediately before death

In the south of South Australia and Western Australia and on the east coast of Australia, community members spoke of how important it was for family to visit the dying person. We were told that hospitals did not cope well with the number of visitors at this time. Similarly, we were told of situations where nurses attending a patient at home had complained about the number of people present. One community member told of a situation where there were many people visiting a person who was dying:

They were there to honour the dying person. The nurse came in and said that there were too many people in the room. She was speaking down to them. She did not understand the cultural importance of the visitors or why they were there. [community member, Western Australia]

Aboriginal people who had used hospices were generally more satisfied with their arrangements, as hospices were often able to accommodate larger numbers of visitors (see Section 5.4 Setting of care). We were told that being able to be with the dying person is important to Aboriginal people in dealing with grief, and so it is important that the dying person is in their own country (see further Section 5.3 Place of Death).

Upon death

Cultural patterns vary across the country. On the east coast of Australia and in the south of South Australia and Western Australia, Aboriginal people said it was important for all family members to be able to visit the deceased person, preferably at the same time so they can talk with each other. This has important implications for the design and management of hospital facilities, and for rules about being able to keep a body at home for a time if this is what the family wants.

¹³ This project did not undertake an in-depth study of grief amongst Indigenous peoples. It sought to explore with participants what their experience had been and if (and how) they thought services could be improved to assist.

In other places, or for families from more traditional areas who may be in Perth or Adelaide, the situation is often different and people will have particular needs related to cultural practices associated with death.

A lady from a remote area died in a Perth hospital. The family members had come to Perth to be with her. The Aboriginal staff from the Aboriginal medical service told the ward staff when she was near death that they should remove solid, moveable objects from the room before she died. They ignored the advice. When she died the waiting relatives began wailing and started hitting themselves with all sorts of dangerous objects that were in the room. The staff had not listened, had not removed the objects and had not found a better room for the lady where the family could be with her safely. [Aboriginal health professional]

In contrast, a senior Aboriginal health worker in Adelaide explained:

Some more traditional families cannot stay nearby when a baby dies in hospital for fear that the spirit of the dying child could go into them. So they may leave the child to die in the hospital.

In some areas of the Northern Territory, South Australia and Western Australia, the bereaved gather in 'sorry camp' upon the death of a community member. 'Sorry camps' usually last for some weeks, from time of death until after the interment. The size of these camps, and the length of time people spend in them may depend on a number of factors, including the age of the deceased, and their standing in the community. The appropriate role of service providers in supporting people in these situations includes assisting with transport, ensuring that those in the camp have adequate food, water and firewood, and providing the medication or medical care the visitors or the bereaved family require.

Funerals

Funerals (and tombstone openings¹⁴) are critical to Aboriginal and Torres Strait Islander peoples' bereavement process, and remain among the most clearly delineated and elaborated elements of contemporary Indigenous cultures, even in areas where other ceremonial life has declined since colonisation. From the perspective of bereavement care, they are an important opportunity for the expression of grief, for the public acknowledgment of grief and for being comforted.

Christian (or Moslem) funerals with hymns and flowers are common, often with Aboriginal or Torres Strait Islander flags, and sometimes incorporating smoking ceremonies. These are critical cultural rituals. In some places people have traditional ceremonies as well as Christian burials. Most Aboriginal and Torres Strait Islander people we spoke with told us how important funerals are, and about the increasing difficulties people have in arranging and attending them. Funerals provide an opportunity to renew family and community relationships, and to share grief with family and community members. For immediate family, the funeral preparation is a vital part of the grieving process, providing rich and valuable opportunities for people to express and deal with grief.

In many places funerals are usually followed by gatherings which are often held in a local community or cultural centre. In most areas of Australia these gatherings also follow well defined cultural protocols.

The support offered by some AMSs to the funeral process is a valid and appropriate provision of bereavement support. At one AMS we visited, AHWs work with the bereaved to assist with practical issues (funding and pension payment issues), facilitate preparation of the 'order of service' and the

¹⁴ for Torres Strait Islander peoples.

eulogies, and liaise with the undertaker or funeral parlour. This very hands-on and practical approach is not only appreciated by the bereaved, it provides opportunities for the AHW to provide informal grief counselling. By being there to talk with family members about the deceased person and about the funeral, they provide a highly culturally appropriate bereavement service. Funerals are not only important to the immediate family but to the whole community. Funerals are central to Aboriginal and Torres Strait Islander grieving and this is reflected in the amount of time people spent telling us about their difficulties in arranging funerals. Section 5.5.8 below outlines some of the difficulties that were reported. The work of AMS staff in assisting with funerals should be a legitimate palliative care expense if staff members have appropriate training to augment their grief counselling capacity.

After the funeral

There was little comment about what happens after the funeral. Most people apparently cope by talking with family. Several people who had been involved with palliative care services said that they had received follow up phone calls offering support in future if required, but though they felt they needed some help they would not ask for it and would certainly not phone for help. Some would have liked a visit.

Community members in Perth thought that some people might like to go to a bereavement counsellor and others might not. There was agreement that some people don't think they need counselling when they probably should have it. More important for Aboriginal people was *'talking time and sorry time and taking time to yarn'*.

An elderly man in South Australia spoke of his devastation after his wife's death. *'Everything was busy 'til the funeral and then there was nothing'* – he was left alone. We were told that in urban areas until recent times the family would provide support, setting up an informal roster of people to be with the bereaved. However this is not happening now that most people have to work and people live further apart and don't have transport. This illustrates the importance of peer support networks and mechanisms (especially for men) as an alternative to professional counsellors.

Some Aboriginal health workers take on an informal unpaid role, visiting and chatting with people. This is as important after the funeral as it is in the early stages of the illness.

The people we spoke with in focus groups very much valued the opportunity to talk to us about their experience. Some people especially thanked us for providing the opportunity for them to speak with others who had been through similar experiences.

5.5.4 What Aboriginal and Torres Strait Islander people said they wanted

Early counselling

In general, Aboriginal and Torres Strait Islander people who had experience of looking after a family member with a life limiting illness said that there should be more emphasis on early counselling, accompanied by better information about the likely course of the illness and what to expect. This early counselling should be undertaken with the assistance of an appropriate Aboriginal or Torres Strait Islander community member, and should ideally be done in several sessions so that people have time to absorb information and to develop trust and a relationship.

There is a lot of grief and sorrow. People try to cope within their own family structure but they can't really address the needs of the person. This is partly because they are not given the

information and counselling that they need. They need counselling so that they can handle the situation and go out and get the services that they need. [South Australia]

The need for early counselling of patient and family was identified by community members in rural and remote Western Australia. This was specifically identified as a need where the diagnosis is done in Perth (away from home).

People are told straight out, and cold hard facts – not told in a supported way. Family is not even there and there is no opportunity to ask the questions that they should ask. They might be offered treatment – might go through all that before they get to talk with any family members. [Western Australia]

Early counselling was also raised by informants on the east coast.

Trained Aboriginal and Torres Strait Islander counsellors

There is a need for Aboriginal and Torres Strait Islander palliative care workers to provide support – ‘someone to talk to’. An Aboriginal doctor in Queensland said:

Being Aboriginal is a benefit – having an Indigenous team, people actually seek to see you. Sometimes they would rather talk to me than a white counsellor in the Centre. Sometimes people don’t get the picture straight up – initially they say they are okay and you see down the track they are not all right.

Clinical staff in one remote community in central Australia reported that last year people spent most of their time attending funerals and this was an ‘enormous part of local culture’.

People are just dying and grief issues are not being dealt with. It does affect families. We need mental health workers who speak [one major regional] language. We are now seeing people with psychosomatic illness – bizarre behaviour – and a number of women needing medication. We don’t have the resources to sit down with people. There is much confusion between traditional beliefs and Christianity. If professionals have no language skills it is very difficult to communicate. There is only so much support you can give.

The remote mental health nurse in this community is sometimes accompanied by a male and female worker. Clinic staff commented that counselling is a highly specialised area and language is a huge issue.

Grief and dealing with death and change – transition between traditional and Western culture – is a huge issue. Counsellors need to have local language skills and be living outside the community so they don’t become overwhelmed by community issues.

Support for cultural protocols

Palliative care workers in the Northern Territory said the most important cultural issues around death and dying for Aboriginal people are family, country and law. These are entwined with protocols (social rules, ceremonies) that are required when someone is sick, dying, or deceased. Supporting these cultural protocols is important for families to assist in meeting their grief and bereavement needs.

Cultural protocols can be very complex in some remote areas or more simple, as in some urban areas. Whether complex or simple, they should be identified and supported by palliative care service providers, preferably with guidance from a local Aboriginal and/or Torres Strait Islander person as cultural broker. Arranging and attending funerals should be seen as a critical cultural issue and palliative care service providers should play an advocacy or facilitating role where needed (see below Section 5.6).

In the Northern Territory, 'sorry business' is considered an important time for dealing with bereavement issues. One Aboriginal service has flexible conditions written into its employment award in recognition of the cultural responsibilities of its staff members and to enable them to attend to such responsibilities during this time.

The high number of deaths in some communities and the cultural responsibilities associated with 'sorry business' can give rise to complex management issues for Aboriginal service provider organisations. In some Aboriginal organisations this is partly overcome by employing non-Aboriginal staff. One organisation told us that it recruited/employed staff from different family groups to ensure there would always be Aboriginal and/or Torres Strait Islander staff on duty.

A major Aboriginal organisation said that the whole organisation will shut down in circumstances where a person who is very important in the community has died.

5.5.5 Barriers to delivering bereavement services to Aboriginal and

Torres Strait Islander clients

As well as the complex cultural issues involved in bereavement for Aboriginal and Torres Strait Islander people and the lack of appropriate services there are some particular barriers to effective service delivery for mainstream service providers:

- the short periods of time spent with Aboriginal clients due to late referral means that ongoing rapport is not established; and
- relocation immediately after death means that follow up is not possible. In some areas people must move house for cultural reasons and may not be easily traceable by service providers;

Most mainstream bereavement services would not be aware of the underlying mental health issues affecting Aboriginal and/or Torres Strait Islander clients.

5.5.6 Innovations and/or good practice in bereavement services

This section highlights the few examples of 'good practice' in this area that were reported.

A Victorian palliative care team has recommended that bereavement plans be prepared in discussion with the local AMS to ensure that culturally sensitive options are available and used.

The palliative care team in a New South Wales rural town suggests working with the community to develop appropriate bereavement strategies for Aboriginal family members in order to offer appropriate support. They suggest that the support is best offered to an identified family or community member who provides support to the bereaved, hence 'supporting the supporter', rather than attempting to directly support the bereaved.

Check that there is a community member supporting the bereaved and then support the supporter, especially at the six week mark. [palliative care service provider]

A service in Adelaide uses group counselling where indicated. Counselling is offered on an individual, family or group basis, including groups for widows and widowers, children, and daughters or sons; and groups are sometimes offered for various adult age ranges. There have been no Aboriginal and Torres Strait Islander groups, but community members thought that would be a good idea.

Aboriginal staff in a number of Aboriginal services in South Australia thought there should also be more and better access to traditional healers who may assist with bereavement.

In a remote area of Western Australia, a Community Health representative who was involved in a recent study of Aboriginal people's health needs reported that people did not want the mental health team to visit because of the social stigma attached to mental health. She said people said they wanted grief counsellors who would sit under a tree where people could go and talk to them.

A Community Health coordinator who had been involved in a recent study in the [remote region] commented that during her discussions with Aboriginal people she was told that counsellors should be from outside the community to ensure confidentiality. An Aboriginal woman also said she would prefer counsellors to be 'kartiya' [non-Aboriginal] for the same reason.

The offer of a palliative care nurse in a remote community in Queensland, to assist with the funeral arrangements was very much appreciated by the community member concerned. The nurse stated that it was '*just the way we do it in New Zealand*'. In some places it may be appropriate for palliative care services to offer this sort of assistance to Aboriginal and/or Torres Strait Islander clients as an effective way to provide bereavement care

An AMS doctor in Western Australia said he believed it was very unlikely that people would take up the offer of formal bereavement counselling (no matter who offered it) and so suggested that bereavement counselling be linked to the practicalities of preparing for the funeral.

Some AMSs assist bereaved families to prepare an 'order of service' and eulogy booklet. This work has had good results but is currently unfunded.

The approach taken by AMSs in assisting with funeral arrangements could be developed and supported by augmenting the skills of staff in bereavement counselling and risk identification, and ensuring that there are adequate staff hours to undertake this work. There is a need for trained staff and funding for bereavement care as an essential element of palliative care.

Strategies for delivering bereavement counselling in a practical and culturally appropriate way should be explored.

5.5.7 Special needs of Aboriginal and Torres Strait Islander health professionals

When there is a death here in the hospital staff experience silent grief because everyone here is related. We empathise with them. There is no counselling for us. We talk to each other. We also visit the family, share stories and unwind with them. The main thing is to empathise – people don't want sympathy – with sympathy you never find the right words. [Torres Strait Islander nurse]

A major issue for Aboriginal and Torres Strait Islander people working in the health system (and in palliative care in particular) is that when a member of the Aboriginal or Torres Strait Islander community dies, they are not only a health professional associated with the event but also (usually) one of the bereaved. Whether as a member of the same extended family or as a member of the local community, they will have been in some way related to the deceased person.

These staff members (AHWs, ALOs, Aboriginal counsellors and nurses) also need appropriate debriefing and counselling.

5.5.8 Issues and problems reported in relation to funerals

The importance of funerals and their role in the grieving process is described above in Section 5.5.3 *Funerals*¹⁵. Many people raised issues regarding funerals, including the cost of funerals, difficulties in attending funerals (cost and transport), and transport of the deceased to the appropriate place of burial.

Cost of funerals

The cost of funerals was seen as a major financial burden, with families often having to go into debt to pay for funerals or tombstone openings. Although many people contribute to various types of funeral funds, there has been a lot of disgruntlement about these funds and uncertainty about what they provide for the money paid.

In remote Western Australia, the cost and the high number of funerals in some remote communities can place a huge financial burden on some families and on the communities. Some cannot afford the cost of the funeral and a body may remain in the morgue for several months until the money is found. In other cases it was reported the community sometimes picks up the cost of chartering a plane and recoups the cost from the family over time.

Funerals are often paid for by pooling family resources ('chuck in') or through a community funeral account.

There was a lot of discussion about the various funeral funds and what they pay for. Some people suggested that there be an enquiry into funeral funds because many people thought that they were being 'ripped off', or being made promises when they signed up only to find out later that what they had been told about entitlements was not correct.

Funerals are so important to Aboriginal and Torres Strait Islander people that they will generally pay what is asked without much question. In Queensland many people contribute \$2-\$3 each week to a funeral fund by direct deduction from their CDEP pay.

Many people reported that notwithstanding costs, they found local undertakers or funeral parlours to be very sensitive to Aboriginal and/or Torres Strait Islander cultural needs, including accommodating special cultural requests.

Accessing funding

Some special funding assistance for funerals is available but many people reported difficulty accessing these funds.

In South Australia it was reported that assistance is provided by Centrelink or by Family and Youth Services (FAYS), although FAYS funds are not available if even one person in the family is employed. (For example four out of five members of a family may be on a pension, but if the fifth is working they would not receive assistance.) We were told of a 90 year old woman who had to pay for her son's funeral because she had more than \$3000 in the bank – her life's savings.

¹⁵ and tombstone openings for Torres Strait Islanders.

The following comments were made in Western Australia:

We need a social worker after the death to help with all the arrangements – prepare eulogy and everything. I needed support to declare my mother dead and all of that – needed to have help in arranging money from Centrelink. [community member]

Centrelink will try to talk a family out of the bereavement package (equal to 3 payments of allowance) – so you need to make sure you send the right person. Centrelink and Family Services will try to knock people back in claiming what they should be able to claim. It depends on which worker you get at Family Services. The AMS provides an advocacy service in dealing with this. [AHW]

Timing of funerals

Funerals often have to be delayed until people can afford to attend. This may have further cost implications for the family as the body must be stored during that time.

Attending funerals – travel

A common complaint was the difficulty of finding transport to attend funerals. In more remote areas people sometimes had to charter flights and were then left with large debts, or were left stranded in communities after the funeral. Similarly, transport to attend funerals was often an issue in urban and rural communities. In South Australia, Victoria and the Northern Territory we were told that community organisations which in the past had permitted their buses to be used for funerals would now no longer do so. It is not clear why this change has come about, but it may be an insurance issue.

Problem of getting people to funerals – can't use community buses any more and people don't have cars. Funding bodies (eg HACC bus) have now said can't use buses for funerals. Community is very critical about this.

If people can't get to funerals then it mucks up the healing process for those who are left behind. [South Australia]

In the Northern Territory lack of transport was a major problem, especially now that it is no longer possible to borrow vehicles from Aboriginal organisations to attend funerals. This can have serious implications for family members who are unable to meet their responsibilities.

Organisations will not loan vehicles even for funerals – not allowed to use bus. Before we used to 'throw in' money for fuel to go to funerals.

Most families here are on a pension. When some family members go to a funeral and others can't because they don't have transport or can't afford to travel, this can cause troubles within the family.

In some parts of New South Wales on the other hand, we were told that Community Options Transport was available for local funerals for a gold coin donation. Travel from rural areas to Sydney (and vice versa) for funerals was, however, a major problem.

Cost of attending funerals

Many people reported having to wait until pension day to travel to a funeral (and to buy good clothes and flowers) and having to wait in the community where the funeral was held until the next pension day to get home. This was a further financial burden on them and the community, and they often had nowhere to stay and no food.

One of the biggest issues for people around funerals is resources to travel to funerals and then somewhere for the family to stay when they arrive. Often people come back to the area for funerals but have to wait two weeks for their next pension cheque before they can travel home again and they have nowhere to stay. [AHW]

Some community organisations in central Australia provide food and blankets for funerals.

Storage and repatriation of deceased

Repatriation

Health systems in all states and territories increasingly recognise the importance of assisting people to get home to country to die, (Williamson 1996; Willis 1999) however if this does not happen, bodies need to be returned to the right place. An AHW in New South Wales said '*Where a person is buried is almost more important than where they die.*'

Transport of bodies for burial can be costly. If the person died in hospital, PATS (Patient Assisted Travel Scheme) assistance is generally available.

In South Australia there have been problems with deaths of Aboriginal people from interstate. It takes time to locate the family and there is no funding to get the body home across state boundaries (eg to Queensland).

In Victoria, the Victorian Advancement League provides a service transporting bodies home for burial and operates across State boundaries. This service was spoken of very highly.

In New South Wales the State government has provided funds to the Mt Druitt AMS to assist with transport of the deceased. This funding covers the vehicle and petrol but not the driver.

The AMS in Kalgoorlie, Western Australia, has provided transport to retrieve bodies from Perth, but this had not been ideal as the vehicle was not refrigerated. The Western Australian government recently modified its rules so that the State government will now fund the repatriation of bodies (beyond 50 kilometres radius of Perth), provided the deceased has been in the care of a hospital.

In the Northern Territory, PATS covers repatriation costs if a client has been relocated to a larger centre for medical treatment and passes away.

Storage

Storage of bodies is a problem in remote areas where there are no morgue facilities. In the Northern Territory, local communities can hold a body only for a day or so before it must be flown out. It often takes longer to arrange the funeral (letting people know, time for people to travel to the community, decisions about where the person should be buried and time needed to get money together). This is also a problem on off shore islands.

One problem might be that there is no place to store the body on the islands so the family or community has to pay for costs of transport. Sometimes the body is flown to other communities for viewing.

In a remote area in Western Australia, health staff mentioned problems with an undertaker from [town] who got lost finding the community. As a result a body was left in the house for two days, which caused cultural problems. In one region bodies are retrieved from communities or remote areas by a contractor, and there were reports of 'rough handling'. There are no body storage facilities in the Aboriginal communities in the region. They either charter a plane for the undertaker to fly out and take the body back to town or he will drive out.

Delays in holding funerals can cause distress and additional cost. In a palliation situation where death is expected, some non-Indigenous care providers (in northern Western Australia and central Australia) have begun to discuss the benefits of holding a family discussion about the place of burial before the death occurs so that delays and extra costs can be avoided. There are clearly difficulties in raising these issues, given the restrictions on speaking about death amongst some Aboriginal and/or Torres Strait Islander peoples, however these services providers believe that attitudes are changing and the idea of having a 'living will' is something that some Aboriginal and/or Torres Strait Islander people might want to speak about.

5.6 Continuity of care: caring at home doesn't mean have to die at home

In the experience of one Northern Territory nurse, the delivery of palliative care has ranged over time from: a) managing people in the community; to b) managing people entirely in the hospital; to c) managing largely in the community up to pre-terminal days and then in hospital.

I have come to doubt whether all people want to die at home. [Aboriginal people's] perspective is varied. It doesn't appear to be the same case for everybody. There are many and varied ways. [Aboriginal people] have different ways of coping. Whatever approach is adopted should be flexible. Often best-laid plans go astray. Caregivers in remote communities may change their minds and we need to accommodate their wishes. [remote clinic nurse]

While many people say they want to look after people at home, in fact many Aboriginal people pass away in hospital. The reasons for this may be related to culture and/or capacity. These issues are discussed in Section 5.3 above.

Relationships between home-based care providers and hospitals or hospices are generally good, but Aboriginal workers including AHLOs, AMSs, and State and community Aboriginal and Torres Strait Islander health units are not in the loop (see further Chapter 8, Section 8.4.4 *Models of coordination*).

There are a number of continuity of care issues for clients returning to remote communities.

Big issue for PC medical officers is how to manage patients in outlying centres. When patients return to their community local GP takes over and provides day-to-day management for these patients but there is still confusion about who is responsible. [field notes, Queensland]

One community member told us that her husband ended up dying in hospital which was not what they had planned. Her husband had been cared for at home for a long time, then things became bad and he went to the hospital because he needed additional medication in the middle of the night. Unfortunately, despite the fact that this person had been a long term

palliative care patient, he was taken to the emergency unit when he presented at the hospital – apparently there were no palliative care beds. He was treated inappropriately, with the emergency staff giving him blood transfusions and trying to ‘make him better’ rather than recognising that he was palliative and probably terminal.

All the good palliative care work of the previous months broke down because there was nothing organised at the hospital and so he was not received as a palliative and terminal patient but as an emergency case. He expressed a desire to go home but it was not possible to extricate him from the system. The emergency unit found a separate room for him but it was not in the palliative care unit. In a sense all the good work of the palliative care team at home was undone at the end because of lack of planning for the terminal stage and probably a lack of information and support at home at this crucial time. This was made worse by the fact that the patient was treated as an emergency patient rather than as in need of palliation.

His wife was very distressed at their losing control of the situation at the end. [field notes, South Australia]

The director of a palliative care unit at a hospital said:

You try to tell people what they should or can do when people are dying: ie that you don’t need to call the ambulance; that you don’t need to call the police etc, but people panic and call the ambulance. Things don’t always go according to plan.

Palliative care patients at one hospital have an ‘alert’ in their case notes to direct them to palliative care if they are admitted to emergency, so palliative care staff in the hospital will be notified if a palliative care patient is brought in. This system doesn’t always work, however, especially if emergency is very busy.

It is critical that palliative care patients be identified if admitted through emergency units. Systems need to be clear so that palliative care patients do not receive inappropriate emergency treatment, for example, they should not be resuscitated if this is not their desire, or have other non-essential intrusive treatment. This issue is especially important for Aboriginal people who are often very daunted by hospital and medical personnel and procedures. In circumstances such as this they may need advocacy support to ensure that appropriate procedures are followed.

5.7 Pain management, medication and equipment

5.7.1 Pain management

An Indigenous doctor said that Aboriginal and Torres Strait Islander patients often do not let you know they are in pain:

We try to make sure they are comfy but sometimes they don’t tell you that they are in pain all the time and it’s sometimes hard to work out – you can sort of work it out if they start to go through a bit of morphine and you say ‘well you must be in a bit of pain’. Sometimes they don’t tell you and you find out from a relative. Then I might talk to people at [the palliative care hospital] and say I think he has had a bit more pain and they get me to increase his medication.

The director of a nursing home in Western Australia was very concerned about pain management for her Aboriginal clients. She said that Aboriginal people did not seem to experience pain in the same way as other people.

A recent publication explains that cultural differences may account for this. While Aboriginal people do experience pain, they may not complain about it or may behave in different ways from other cultural groups in coping with pain (Fenwick 2001).

5.7.2 Cost and perceived cost of medication

The cost of medication was said to be a problem for community members in all States and Territories we visited. Even where medication is on the 'free' list, dispensing charges were seen as a burden. Sometimes people would be prescribed 'second choice' drugs because they could not afford the most effective ones. It was reported that many community members would choose to spend money on other family needs before they would spend money on medications.

Palliative care workers need to check that the family can afford the medication prescribed or facilitate finding financial support for medication.

We were told by Aboriginal health workers that the fear of the cost of medication is probably one reason why Aboriginal people do not seek medical assistance. A palliative care service for Aboriginal and Torres Strait Islander people should include checking to see that medications prescribed will be available and accessible as a key feature. There may be an advocacy role for palliative care providers in relation to medication.

Low levels of income amongst many Aboriginal families mean that these families cannot afford even basic things like fees for meals-on-wheels or the cost of having a prescription filled. Any money that is available goes into supporting the extended family rather than into medication, equipment costs or other service. [Western Australia AMS staff member] Note: This person was under the impression that there was a fee for Silver Chain Palliative Care services.

5.7.3 Appropriateness of medication

Availability and suitability of prescription

A number of community members raised issues concerning availability of medication. Apparently medication may be prescribed which chemists do not necessarily have in stock (and cannot get without notice). It was suggested that palliative care workers could facilitate access to medication by checking with local chemists about availability and by advising carers to phone the chemist in advance to order stock.

A patient returning from Adelaide was seen getting off a bus in his country town. He had been prescribed Ketamine and Fentanyl via subcutaneous pump. No pharmacy in his home town was able to fill his script. [reported by a doctor in South Australia]

If the client is returning to a remote or regional centre, it is critical that availability of medication be checked and arrangements made for its supply, or a more appropriate medication arranged.

High mobility affects access to medication. *‘Often when people go to visit family in other communities they take nothing with them, including their medications.’* [Queensland]

We received some reports of some forms of medication being withheld from Aboriginal clients because of perceived safety issues in Aboriginal households. The rules about the administration of drugs should be explained carefully to clients and all the possible options should be explored, not just what can't be done, but how it could be made to work in the particular situation.

5.7.4 Inappropriate drugs and inadequate monitoring

In some places in the Northern Territory local doctors' attitudes to pain management and reluctance to use morphine because of legal implications has meant that the palliative care workers have had to ask the palliative care medical officer from a nearby centre to intervene on behalf of clients.

In New South Wales palliative care service providers and nursing home directors reported prescription of inappropriate drugs for terminally ill patients – *‘not the best possible choice being made’* – largely due to the inexperience of GPs.

There were many reports of undesirable effects of the use of MS Contin without adequate bowel care.

5.7.5 Issues about Morphine

Fear and misunderstanding

In one rural area of New South Wales a community member explained that there was widespread fear of being given morphine close to the end of life because of a belief that it would hasten death. The common belief was *‘If you go into hospital they will give you the injection and you will die’*. An AMS doctor said that many local Aboriginal people had a great fear of needles generally.

An ALO in Brisbane said she felt for families because a lot of time they have to deliver the morphine and this is very stressful for the daughter/wife/family.

They [health professionals] come and leave the stuff but you are left to administer the stuff and it's very hard. Lot of times they are not giving them the full dose because they are too frightened. He's in pain – just give a little to ease a little bit – not going to give the full dose because that's going to kill him.

This ALO also talked about the fear patients have of receiving morphine and was present when a patient who was about to be given morphine said:

My aunty had morphine and she died so what are you trying to do to me, are you trying to get rid of me?

She said Indigenous people often do not understand about drugs or palliative care:

A lot of our Indigenous community don't understand about drugs – the palliative care side of things. My husband went in for an operation and they were going to give him morphine and he was so worried. He knew his brother had had it, his mother had had it and they both passed away. He freaked out.

Staff from one palliative care service emphasised how important trust was in the administration of medication. In relation to morphine there was a need for accurate information and there were many myths about morphine which should be dispelled.

In Queensland people spoke a lot about their fear of morphine. One woman told a story of her husband who was dying of cancer:

He had come home to the local hospital and he sat on the veranda for 2 days and nights receiving visitors and the nursing staff had to try and get him to rest. On the third day he was exhausted. At the end they called the family together and asked about giving him some additional morphine to help with his breathing which had become very shallow. We were informed that his heart was under a lot of strain. He passed away shortly afterwards. That was such a shock and it took my daughter and me a long time to get over it. My daughter felt so guilty – she felt she was part of a decision which killed him. She eventually dealt with this through talking to family and friends. [Queensland regional area 3]

and:

When my sister in law was dying of cancer she said she didn't want an extra shot of morphine at the end – she wanted to die naturally. She did but she was fighting hard for her breath right to the last. [Queensland regional area 3]

People who go on to morphine die more quickly – without morphine have more days.

For many people when they hear the word 'morphine' that means death. It is the last option and they don't want their relative to go on morphine. When they see it going in [being administered] they know they are going to 'go'. It is the end and they are definitely going to die.

Misunderstandings of and fear about morphine have led to the production of a useful resource in Queensland, *Understanding Morphine*¹⁶ which was compiled by Mount Isa District Palliative Care Service to answer patients' and carers' questions about pain relief in plain language.

Access, safety and security

We were told stories of patients having to receive care in hospital because the service providers would not prescribe drugs for administration at home because of lack of safety and security.

In remote areas, the major issue raised about morphine was the difficulty of access to it and appropriate storage facilities.

Administration of morphine in aged care and nursing homes

In several States, aged care and nursing home facilities reported difficulties in being able to provide adequate palliative care because of rules about the administration of dangerous drugs. The requirement for two registered nurses to be present (when the home was not funded for this) meant that the client had to relocate to a high care facility or to a private home. In some States, palliative care services can and do consult into aged care facilities, however there are sometimes difficulties in palliative care nurses (eg domiciliary nurses) going in to provide medication because of funding issues and drugs administration

¹⁶ Available from Mount Isa District Palliative Care Service (07) 4744 4828 or Queensland Cancer Fund (07) 3258 2200, it is beautifully illustrated by local Aboriginal artists Harry and Shannon Gertz, and is 'user-friendly' for Aboriginal patients and their families.

rules. Funding rules and drug administration rules need to be modified so that residents of aged care facilities and nursing homes can receive the best possible palliative care (including appropriate pain management and cultural security) in their place of residence.

5.7.6 Equipment

The major issue relating to equipment was that Aboriginal and Torres Strait Islander people looking after terminally ill relatives at home did not have information about what equipment would help them or how to access it. This was especially the case where they had not had the support of palliative care workers. Even where families were receiving palliative care services, access to equipment was sometimes a problem and people had to try to source it themselves.

One of the issues raised was that some service providers were concerned about the eventual return of the equipment because of the mobility of Aboriginal and Torres Strait Islander people or the condition of their houses. Sometimes the housing did not lend itself to accommodating appropriate equipment such as hospital beds. Spaces were too small, for example. Many community members who had been provided with equipment such as proper beds or bedding, lifters, wheelchairs, etc, said it was one of the good things about palliative care and made a big difference.

In New South Wales, service providers also reported that access to, storage of, and transport of equipment was a problem. There are often waiting lists for items such as oxygen concentrators and generally funding is not available for transporting equipment. In the Northern Territory, service providers said that they often did not expect to get equipment back. (For example, especially in remote communities, all resources are valuable and maximum use is made of them. For old people, wheelchairs are valuable for other practical purposes such as to collect firewood). In the Northern Territory the cost of delivering an oxygen concentrator to a remote community was about \$400. Detailed and well coordinated discharge planning could reduce these costs by ensuring that equipment is transported on the same plane as the patient.

In the Northern Territory, a palliative care team has experienced problems of clients running out of medications because they had not understood about getting repeat prescriptions. A number of AMS services dispense medication in order to avoid some of these problems.

In one regional area of Queensland an ALO said:

Medical aids are a big problem with our Indigenous people here. We have Community Health – we can plug into their resources – and there is a MAS (Medical Aids Scheme) program where you can purchase stuff, but the process takes too long for people to access the medical aids. Wheelchairs – there is often a shortage for mainstream as well. People sometimes die before we can get the equipment. [hospital ALO]

5.7.7 Equipment infrastructure costs

Many people raised the issue of hidden costs in palliative care such as the cost of increased gas or power consumption for heating or running equipment. Some people said that they were still paying off their energy bills two years after the death of a family member.

5.8 Service provider access to palliative care specialists

The palliative care worker estimated 99% of palliative care work is counselling talking, educating – bringing everyone together [Western Australia rural area]

Good palliative care is a well coordinated service, where someone (such as a GP or AMS doctor, a palliative care service or a family member) brings together all the various elements necessary to deliver appropriate care (for example, symptom management specialists, ancillary services such as physiotherapists, equipment providers, home help, cultural interpreters and grief and loss support).

5.8.1 Symptom management advice

Access to all of these elements is important but for symptom management, specialist advice can be critical. This need has been recognised and many services are set up to access specialist doctors or nurses. In many places, palliative care advice lines have been set up for doctors and/or nurses, however these are not always well known and are often not used by GPs and AMS doctors. Advice lines and personal networks are especially valuable to nurses working in relative isolation in remote communities or small towns. Where specialist doctors are not available in a region and no advice line exists, local palliative care nursing staff will call a big city hospital for advice. Many have developed their own advice networks. Palliative care providers state, however, that GPs who do not recognise that they need advice are the problem – not the lack of advice opportunities.

In Adelaide, an innovative system of outreach has been developed in which doctors from Adelaide palliative care units perform outreach visits to various parts of the State (certain city hospitals deal with certain parts of the state). To an outsider there appears little logic in the way the State is divided for this program. Specialists from Adelaide visit regional palliative care units and provide education programs and consulting advice. It appears, however, that only some palliative care staff are accessing the educational or consulting sessions. In one area where we conducted phone interviews, the community based unit was involved in the program but staff at the hospital (which had a palliative care bed) was not. The staff in the regions value this outreach greatly.

In remote communities in central Australia, clinic staff are only able to provide palliative care because they have phone access to the Territory Palliative Care Service whenever they need it.

5.8.2 After hours advice for clients

Client access to after hours palliative care advice varies enormously and service providers have identified this as a critical need. It is especially heartbreaking for family and service providers if the care and comfort provided by a palliative approach breaks down at the end because a crisis occurs at night or on a weekend when no staff are available to deal with it. Carers often panic and call an ambulance, and the client ends up in the hospital emergency unit, receiving inappropriate treatment.

After hours emergency numbers will only be useful to Aboriginal and Torres Strait Islander clients if they have a telephone. In urban areas many Aboriginal and Torres Strait Islander homes do not have phones. Consideration should be given to funding telephone access to service providers for palliative care clients in areas where this is possible. In remote areas, client access to specialist advice is even more difficult since telephones are even rarer and after hours emergency lines are unlikely to be available because of low staff levels.

Some implications of these findings are discussed in section 5.9.8.

5.9 Findings and implications

5.9.1 Expectations, attitudes and relationships

Past experience has a powerful impact on whether Aboriginal and Torres Strait Islander people will be willing to accept referrals to palliative care. Their underlying experience of and attitude towards the health system and towards non-Indigenous bureaucrats and service providers is a critical constraint on effective service delivery. In general, Aboriginal and Torres Strait Islander people strongly dislike, distrust and fear hospitals and non-Indigenous strangers coming to their homes.

Mainstream service providers should acknowledge these attitudes and the historical reasons for them. ACCHSs exist in order to overcome some of these difficulties and to allow community control of health service delivery. ACCHSs should be invited to become a central part of the specialist palliative care network and/or palliative care service providers should put their specialist skills at the disposal of these units, especially where they have mutual clients.

Service providers, in turn, hold attitudes which affect their behaviour towards Aboriginal and Torres Strait Islander clients. Many people who work in these fields have never met or spoken with an Aboriginal or Torres Strait Islander person and know little, or nothing, about Aboriginal and Torres Strait Islander health services. Unfortunately, many are perceived as highly judgmental by Aboriginal and Torres Strait Islander people. Most, for example, are unaware of complex family relationships or the group nature of many Aboriginal households and do not understand the implications of these when home visiting. Many would not feel comfortable in the conditions of many Aboriginal and Torres Strait Islander households. Concerns about hygiene and personal safety (both perceived and real) were reported. For their part, we were told that many Aboriginal and Torres Strait Islander people feel 'shame' when non-Indigenous strangers visit their home.

The attitudes and expectations of clients and service providers have very real significance for discharge planning and assessment and care planning. The importance of the referral process and the need for cultural advocacy at this time has been mentioned above. In hand with this is the need for the development of trust between clients and service providers. Development of trust requires the development of a relationship. In many cases, because of late referral there is not enough time for this relationship to develop.

Service providers working with Aboriginal and Torres Strait Islander clients should start to develop relationships with the community by beginning a dialogue with Aboriginal and community organisations (including health and home care providers). They need to establish their 'credentials' in the community. Being introduced or recommended by a community member is an almost essential first step to forming a relationship and is particularly critical where time is short.

Immediate action that service providers can take would be to initiate a local dialogue between mainstream and Indigenous service providers to find out what each does, what each has to offer and to work out how the gaps can be filled. The solutions should be developed in response to local circumstances and cultural needs. This action can be taken by individual service providers and/or Indigenous health services. It should be encouraged and supported by State governments and non-government bodies.

5.9.2 Discharge planning and assessment

There is a need to develop care pathways for palliative care clients which ensure consistent involvement of the palliative care team, a cultural advocate¹⁷ (AHLO or AHW from AMS or Indigenous staff of the service providers) and appropriate family members in discharge planning.

A question about Indigenous status should be asked on admission as a palliative care client (with an explanation of why it is being asked). Assessment should not take place without the participation of appropriate Indigenous staff. Assessment processes should try to avoid a stream of individual service providers and may need to be done over several visits as relationships develop. The location of the assessment (including the place it is done in the home) and the language and listening skills used are crucial. Understanding the relationships of family members and realising that roles within the family may be culturally determined are also critical. The carer may not be the decision maker. Service providers should work with Indigenous staff and/or community advisers to develop effective assessment processes for their particular situation.

Service providers should ensure that they have ready access to, and funding for, a cultural specialist and should develop ongoing relationships with local Aboriginal and Torres Strait Islander health and community organisations.

National Palliative Care Strategy (NPCS) Goal 3 *Partnerships in care*, would be enhanced by an introductory objective about raising the profile of mainstream service providers in the Indigenous community, including naming specific individuals as contact people for Indigenous clients and services, so that relationships can be developed and so that people can get to first base in developing care planning (see further Chapter 10, Section 10.2.3).

5.9.3 Implications of place of death issues for service providers and policy makers

The implications of place of death issues discussed in Section 5.3 above are set out below.

Early information, being prepared and making a choice

The earlier clients and their families are informed of their condition (in a culturally supported way) and of the options and support services that are available, the better they are able to make an informed choice about where they want to pass away and to put in place the services that will achieve that. The fact that diagnosis and/or referrals to palliative care services are made very late reduces peoples' freedom of choice.

In remote areas, careful consideration should be given to whether to send someone away to the city or regional centre for treatment or diagnosis if there is a chance that they will not be able to get back in time. Better use of telemedicine may assist. Families should be involved in these choices.

Better information

People need and want better information about the likely progress of a disease, about the process of death and what to expect, about what can happen after death (length of time the deceased can be kept at home) and about the sorts of equipment, services and options that are available. Publications such as *Palliative Caring at Home*¹⁸ should be reviewed and revised to meet the needs of Aboriginal and Torres Strait Islander people and should be made widely available through Aboriginal or Torres Strait Islander health services.

¹⁷ Unless this is expressly rejected.

¹⁸ *Palliative Caring at Home* (WA), Palliative Care WA, Silver Chain and the Cancer Foundation of Western Australia.

Solutions for cultural dilemmas

Solutions for cultural dilemmas in relation to place of death should be explored where necessary, for example:

- provision of a detached room (with visitors facilities) adjacent to the clinic in remote communities (see above);
- building of a 'care centre' separate from, but possibly adjacent to, a town hospital where family can come to be with a dying person; and
- provision of a suitable comfortable house made available for the duration of the palliation which would allow the family to care for the person and vacate the premises upon death.

Advocating on behalf of clients to get them home

Some service providers do not do enough to help people get home. Palliative care service providers and Aboriginal medical services in cities should actively advocate on behalf of their clients to find a way for them to return home, rather than simply assuming that it isn't possible. Some clients would rather be at home with slightly less effective symptom management rather than away from home with more comfort.

Improvement of hospital and nursing home facilities

Ensure provision of the following:

- separate rooms for the dying person which are large enough to accommodate family groups;
- rooms which are on the ground floor and have outside access;
- special, large family visiting rooms such as that at Goulburn Valley Base Hospital (see Appendix 9); and
- a large pleasant room where the deceased can be visited.

See further Section 5.4.3 Setting of care - care in hospital)

Tracking systems

Development of tagging or tracking systems are needed so that if a palliative care patient arrives at hospital their condition will be known, the palliative care team can be contacted and they will not receive inappropriate treatment (see Section 5.6 Continuity of care).

5.9.4 Setting of care

Care at Home

Care at home was the preferred option of most people we spoke with. Issues identified to improve this included:

- service provider visits should be made in company of Indigenous staff;
- taking the time (and having the skills) to establish a relationship;
- competence in cross cultural communication and practice;
- being sure to establish who are the decision-makers in the household;
- coordinating and reorganising services to reduce the number of strangers coming to the house;

- providing appropriate information on a range of issues and delivering these both verbally and in written form; and
- maintaining confidentiality and being discrete.

Having enough respite care services available to give carers a break is critical to most people's capacity to care at home.

The most appropriate role for the palliative care worker will be determined by the context in which they are working. For home-based care, the model that best accorded with what Aboriginal and Torres Strait Islander informants said they wanted was to act as a coach to support and train the family so that they could undertake the care.

Hospital and hospice

Hospitals are often seen as places of death rather than of healing by many Aboriginal and Torres Strait Islander people and many communities are acutely aware of relatively recent racist practices, such as segregated wards, and labelling of cutlery and linen for Aboriginal patients.

The design and decorations of hospices and hospitals should be reviewed to attempt to implement the many physical improvements that have been identified above.

Staffing and care practices at hospitals should be reviewed to:

- increase the number of Aboriginal and Torres Strait Islander staff at all levels;
- ensure that good quality cultural awareness training (which covers end of life issues) is provided to all staff regularly;
- ensure medical and cultural advocacy for Aboriginal and Torres Strait Islander clients; and
- facilitate the involvement of family in the care of patients.

Hospitals should put in place appropriate protocols for meeting end of life (and post death) requirements of clients.

Familiarisation visits to hospitals and hospices for key members of the community can be effective in dispelling misunderstandings about hospices. Consultation with community leaders about how to make hospitals more comfortable places for Aboriginal and Torres Strait Islander peoples would be appropriate.

Nursing homes and aged care facilities

- There is a need for more flexible and generous funding arrangements to ensure that funding is not a barrier to aged care facilities and nursing homes accessing appropriate palliative care for their clients. The model recently developed in Perth seems appropriate. Silver Chain Palliative Care Service delivers services into nursing homes in the metropolitan area provided the homes do not have 24 hour care. If they have 24-hour care then Silver Chair delivers a 24 hour consultancy service as a five-day package, funded by the State government.
- All nursing homes and aged care facilities should be encouraged to access palliative care services for assistance and advice regarding palliative care clients.
- Mainstream nursing homes and aged care facilities should be encouraged to access Aboriginal and/or Torres Strait Islander health and community services to support their Aboriginal and Torres Strait Islander clients and their families (unless clients do not desire this). It may be appropriate to include

these organisations in the care planning for Aboriginal and Torres Strait Islander clients and/or to broker in their services for family liaison and cultural advocacy. The use of video conferencing with families of remote residents should be explored.

- Local palliative care teams should include residential facilities as part of their support, education and clinical program. Offering in-service training to these facilities may begin a useful relationship.
- Nursing homes and aged care facilities in areas with substantial Aboriginal and/or Torres Strait Islander populations should endeavour to increase the number of Aboriginal and/or Torres Strait Islander staff (at all levels including nursing, caring and domestic) and in some places should develop strategies to ensure that there will be enough staff to back-fill positions when staff have to go on 'sorry' (bereavement) leave. Employment of both male and female workers is important because of cultural avoidance issues which prevent some people caring for others.
- Mainstream nursing homes and aged care facilities which have Aboriginal and Torres Strait Islander clients (or which are in areas that have large Aboriginal or Torres Strait Islander populations) should have positions designated for Aboriginal and Torres Strait Islander staff.
- Nursing homes and aged care facilities should ensure that all staff have undertaken cultural awareness training. Cultural sensitivity should be included as a performance measure in evaluations of service delivery.
- Nursing home staff should have palliative care training (see also Chapter 7, Section 7.6.3).
- People living in nursing homes need to be able to make the choice to go home to country to pass away if this is what they want. They need information to be able to make the choice in enough time to get home. Sometimes people will choose to return to country even though there are no care facilities for them. This is their right.

Need for medically supported hostels and palliative care for itinerant people

In cities such as Perth and Adelaide and in Alice Springs a need was identified for medically supported hostels for short term accommodation of Aboriginal and Torres Strait Islander palliative care clients visiting for medical treatment (see Section 5.4.6) .

There is a need to develop strategies and funding arrangements to allow delivery of palliative care services to all people in the setting of their choice. This should include itinerant or 'homeless' people who need palliative care and symptom management.

5.9.5 Counselling and bereavement care

The main implications from the findings reported in Section 5.5 are:

- need for more trained Aboriginal and Torres Strait Islander psychologists and counsellors;
- need for AHW post graduate qualifications in grief and loss counselling;
- need for recognition and recompense for work of AHWs that is currently done in their own time;
- need for support groups – both for families of people with life limiting illness and/or for families of who have passed away; and
- need to involve Aboriginal and Torres Strait Islander palliative care workers as part of palliative care team (may be brokered in from AMS or other services) to ensure that early counselling takes place.

- need emphasis on early referrals and early counselling, and need to establish what people want, where they want it to happen and to facilitate this;
- palliative care teams should work with local AMSs and other community groups to develop bereavement plan options that are culturally sensitive. These should take into account that
- ‘*Aboriginal people won’t ask*’ for services,
- ‘*We value someone who will take the time to have a yarn*’,
- ‘*We might want to talk to someone from outside the community*’ – ensure that appropriate ‘third party’ services are available;
- continue strategies to remove stigma attached to attending mental health services;
- service providers should explore the idea of ‘*supporting the supporter*’;
- ways to combine professional bereavement counselling with practical assistance and advocacy should be explored, as in the case of the AMS which provides the services of AHWs to help write eulogies and the ‘order of service’. Assistance with family funeral preparations by health workers whose skills have been augmented by grief and loss training should be considered a legitimate health cost;
- recruitment of Aboriginal and Torres Strait Islander people into volunteer programs is needed;
- need for research into best approaches to assist in management of grief and loss for Aboriginal and Torres Strait Islander communities;
- service providers should check that the bereavement services they are offering are appropriate and where possible should make use of, or seek advice from, an AMS emotional and social well-being service or other Aboriginal counselling services; and
- put in place appropriate counselling and debriefing services for Aboriginal and Torres Strait Islander health professionals who deal with death on a regular basis as they are usually members of the bereaved families or are connected with the deceased.

5.9.6 Continuity of care

Being cared for at home does not mean that one has to pass away at home, and being cared for in a home or hospital does not mean one cannot pass away at home. Flexible and responsive services should allow for patients and families to be able to choose the options they want, and to change their minds if the situation requires it. Palliative care pathways and patient tracking systems will support consistency of care. NPCS Objective 2.4 should be developed to ensure that systems are developed which deliver consistency of care and which have built into them key points which will identify the need for cultural advocacy.

5.9.7 Pain management, medication and equipment

The major issues here relate to how Indigenous people experience pain, the need for information about pain management, and the cost and perceived cost of medication (see Section 5.7). Many Aboriginal and Torres Strait Islander people cannot afford the dispensing fees let alone the cost of medication which is not available on the Pharmaceutical Benefits Scheme. People often go without medication to pay for other family needs.

There were many reported cases of doctors prescribing inappropriate medications, that were either not the most suitable for symptom management, or that would not be available or able to be administered when the patient returned home. There were numerous stories of clients arriving home in remote communities with prescriptions for medication that was unavailable in the community.

There are many issues of concern about the use of morphine. Many Aboriginal and Torres Strait Islander people are fearful of morphine and there are apparently many misunderstandings about its use. There are also safety and security issues about access to this drug by palliative care clients. Issues concerning equipment shortages are reported in Chapter 9 below.

5.9.8 Access to palliative care specialists

The implications of the findings in Section 5.8 above are:

- the existence of palliative care service and advice lines should be marketed to GPs and AMS doctors;
- service providers should keep in mind that Aboriginal and Torres Strait Islander clients may not have telephone access and should either advocate for phone access on their behalf or set up emergency procedures that do not rely on phones;
- funding structures should be examined to allow for the funding of telephones for palliative care clients who otherwise would not have them; and
- service providers should budget for the employment or brokering in of Aboriginal and/or Torres Strait Islander cultural specialists who could be on call to provide advice.

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Chapter 6

Workforce issues



6.1 Traditional healers

As explained in Chapter 4, traditional healers are used quite extensively in some parts of the country and are sometimes consulted by palliative care clients and their families. The use of traditional healers is fairly well supported by community-controlled health organisations and organisations (such as the Ngaanyatjara Pitantjatjara Yankunytjatjara [NPY] Women's Council) in remote areas where traditional practices continue.

We did not find traditional healers working specifically or formally in palliative care; rather they were providing services to sick people either privately or during a special clinic at a community-controlled health centre. In some cases healers may play an important role in confirming to the family that the medical view that the client requires palliation rather than healing is, in their view, correct. They can also have an ongoing role in pain and symptom relief.

No significant barriers to traditional healers visiting clients in hospital were reported, however it is not known whether the hospitals concerned were aware of the nature and purpose of the visits.

In central Australia there is considerable debate about pay rates for traditional healers. In some places they receive 'top up' on their CDEP pay. In others they are apparently fully employed and are paid as health workers. These sorts of debates also raise questions about insurance, equity, accountability and other issues. In the Northern Territory there is a strong view that decisions around the use of traditional healers should be left to the community and that it is not an issue for government.

6.1.1 Western Australia

Aboriginal people use traditional healers and bush medicines to treat illness in many Western Australian communities. One administrator expressed concern about 'medicalising' a practice that exists in many areas anyway and felt that the most important thing was to support the process.

Peter Williamson's 1996 report (Williamson 1996), recommended that *maparn* (traditional healers) in the Kimberley and Pilbara regions should be involved in the delivery of palliative care to Aboriginal people from the early stages of a terminal illness, if that is the patient's wish.

6.1.2 Northern Territory

In many remote communities, traditional healers are involved as a matter of course. At Yuendumu in central Australia, *ngangkaxis* (traditional healers) were placed at the top of the list of people who should be involved in caring for someone who is 'finishing up'.

The NPY Women's Council employs *ngangkaxis* in the communities it serves.

6.1.3 South Australia

Nganampa Health facilitates the use of *ngangkari*s where this is desired and will also fly them to Port Augusta or Adelaide if this is requested by clients who have had to go away for treatment.

Some other Aboriginal medical services (eg Nunkawarrin Yunti in Adelaide and Pika Wiya in Port Augusta) also engage traditional healers to run clinics or visit clients when necessary or when there is a *ngangkari* available. The healers will visit other service providers in the area as well (eg Wami Kata aged care facility in Port Augusta). Service providers report that it is increasingly hard to gain ready access to these healers.

Traditional healers are also employed at Koonibba (Ceduna) and Umoona (Coober Pedy).

The implications of the use of traditional healers in relation to palliative care are discussed below in Section 6.8.

6.2 Aids in nursing

Aboriginal staff working in nursing homes sometimes hold the aids in nursing (AIN) qualification. The director of one Indigenous-specific nursing home expressed the view that AIN training should be expanded to include a palliative care component.

6.3 Aboriginal Liaison Officers (ALOs)

6.3.1 Role and qualifications

The role of hospital Aboriginal liaison officers is very broad and may include liaison between clients and the hospital, and between tertiary and primary health care providers. Their presence serves to alleviate the sense of isolation that Aboriginal people and Torres Strait Islanders feel in the institutional setting of a hospital. Their continued use was a specific recommendation of the Royal Commission into Aboriginal Deaths in Custody (RCIADIC) (Johnston 1991)¹, which recommended that their use as part of the therapeutic team be increased.

ALOs are usually employed by hospitals which have significant numbers of Aboriginal and/or Torres Strait Islander clients, though the hospitals' criteria for employment of ALOs was not investigated as part of this study and may vary from State to State.

The ALO's role is generally that of a social worker, liaising between various services, assisting people to get to appointments or fill out forms, sorting out financial issues, transport, family liaison etc. ALOs are not often involved (in a clinical sense) 'as members of the therapeutic team' as recommended by RCIADIC and are seldom involved in discharge planning in any substantial way. In some places we were told that even if they had a comment, their views could not be included in the clinical notes because they were not clinicians.

ALOs are often called on to liaise into the community as well as directly with patients. Some are responsible for cultural awareness training of other hospital staff, a role which some thought was inappropriate². Some are called upon for language translation and some provide advice on cultural issues.

¹ Recommendation 261: *That the use of Aboriginal hospital liaison officers as part of the therapeutic team is increased.*

² There are questions about whether ALOs are the best qualified to provide this training. Most are not skilled trainers. It may also be inappropriate, ineffective or difficult for an ALO to train staff who may be in a more senior or supervisory role.

Many of the ALOs we spoke with had no qualifications, though others had received health worker training and some had degrees in social work. In Darwin, Aboriginal hospital liaison staff have health worker qualifications, but are apparently not permitted to do any clinical work, in contrast to health workers based in remote communities. Most ALOs do not provide 'medical advocacy' (acting as translator to the medical profession) or are not qualified to do so, though some may have AHW qualifications.

Some ALOs spoke of the need for ALOs to accompany doctors on rounds to explain to patients in plain language what their situation is. This does not always happen.

ALO's gave an example of a doctor wanting to turn off life support [to a young baby] at a particular time and not giving the mother time to consult with appropriate family members. They see it is their role to make sure this sort of thing doesn't happen. [Queensland]

Some AHWs and Aboriginal health administrators suggested to us that hospitals prefer to describe their staff as 'ALOs' so they would not have to employ qualified AHWs or RNs and pay them more.

In Perth, a hospital liaison team services the major hospitals in relation to clients from remote communities. This team is located independently of the hospitals it serves. These staff all have nursing qualifications which are vital to the role they play in explaining medical issues to patients and their families. Only one member of this team is Aboriginal.

At least one remote community health organisation employs its own (2.5) hospital liaison officers, based in Alice Springs. Their role is to transport patients and their escorts to and from medical appointments, check that flight and bus connections will work and sort out accommodation issues.

On Thursday Island in the Torres Strait there are high numbers of Indigenous staff in the hospital (nurses and ancillary staff) and ALOs are not employed. Any one of a number of people are likely to fill the ALO role, though at the expense of other duties.

Without exception, the ALOs we spoke with were overworked and often unsupported. There is no career structure for ALOs. Many had no access to hospital transport for community liaison work. Some reported difficulty accessing funds for certain purposes, such as to provide sandwiches for family visitors who may have travelled all day to reach the hospital. Some complained that they had no office space and no private area to take a family in the event of a death in the ward.

Some hospitals employ a male and a female ALO, but this is not the norm and in many places the ALO is the only Aboriginal or Torres Strait Islander employee in the hospital. In these circumstances they feel very isolated.

ALOs generally reported being very stressed by their workload and by the deaths of clients (who were often family or friends). They do not receive adequate debriefing or support to deal with grief issues associated with their work. There is a very high turnover of ALOs.

6.3.2 ALOs and palliative care

ALOs are generally not involved in liaison with palliative care units, either in the hospital or in the community, nor in discharge planning for palliative care clients. Unless funding were to be made available for additional hours or staff, ALOs would not have the capacity to be involved and in general they do not have the training to fulfil these roles.

Although hospital-based ALOs are very overworked, one might have expected a greater degree of liaison between them and palliative care services. In fact we often found that the palliative care service (even hospital-based units) had no contact with the ALO at the hospital and some were even unaware of their existence.

Sometimes palliative care staff claimed that the ALO would be involved if there were Indigenous clients, but the ALO said this did not occur. (Several of these discussions took place with both the ALO and the palliative care staff present and provided useful opportunities for an exchange of views and identification of needs.)

Some ALOs thought that it should be their role to let families know what palliative care services are available but this could not be done without more staff. Some spoke of the need for both male and female ALOs and, in the Northern Territory, of the need for ALOs working in palliative care to be 'neutral' (for example the Aboriginal worker for the Top End palliative care service comes from Western Australia) to avoid cultural restrictions which would prevent them from working with some people. In Perth a need for Wongi and Kimberley ALOs, as well as local Noongar staff, was reported. Many people stressed the importance of employing local people who have good links with the local community.

Some ALOs said that palliative care should not be part of their duties because they already have too many roles to play. Many said that they should be involved but could not do so without additional hours or more staff. ALO working hours are 9.00 – 5.00 only and some work only two or three days per week.

At a major base hospital in Queensland, the palliative care unit spoke of the importance of their relationship with ALOs for development of relationships with the community.

The implications for the role and participation of ALOs in palliative care are discussed in Section 6.8 below.

6.4 Health and Community Care (HACC) Workers

Indigenous HACC workers who often the first Aboriginal or Torres Strait Islander workers to come in contact with Indigenous clients who need palliative care.

Aboriginal homecare coordinators in several locations in New South Wales reported that they are often asked to provide personal care, home care or respite care for palliative care patients (who were not clients of palliative care services), usually after being approached by the family or by the AMS. Wagstaff (1997) documented similar occurrences in Victoria, as did Williamson (1996) in the Kimberley and Pilbara. In New South Wales, one hospital ALO stated that she regularly referred clients to the Aboriginal home care service rather than to the palliative care service because she thought that people would not want to use a service that *'doesn't have a black face'*.

One Aboriginal domiciliary care worker in Adelaide provides services to palliative care clients as well as other clients.

Many HACC services reported difficulties in providing services to clients who do not fit the HACC criteria (or who have become palliative and are no longer covered by the funding guidelines) but provided the service anyway. *'We find the money somehow or we do it in our own time.'* Palliative care is generally no longer covered by HACC funding arrangements (see Chapter 9).

In some Indigenous HACC programs, especially those run out of AMSs, the HACC workers are often involved in caring for palliative care clients (regardless of whether they fit the HACC criteria). As well as

providing home care services, the HACC workers act as counsellors and coordinate other services. They are often not in contact with palliative care services, are not trained to undertake this work and often work in their own time.

Indigenous HACC programs in which Aboriginal and Torres Strait Islander workers provide home services have been very successful in servicing Aboriginal and Torres Strait Islander clients. These programs are often able to coordinate well with a range of mainstream services. One reason is that funds have been provided for Indigenous staff in HACC and CACP programs and in some places have also been provided for the employment of Indigenous HACC development officers. These development staff work across a number of (usually mainstream) services providing cultural awareness training, checking that Indigenous clients are receiving adequate services, and advocating on behalf of Aboriginal clients when needed.

For example in a regional centre in Victoria, the HACC Aboriginal liaison officer/ Development worker not only provides direct liaison to clients but also works with mainstream services to check the suitability of their policies and procedures, and regularly runs cultural awareness training programs.

It is also noted that the HACC National Reference Committee has been instrumental in bringing Indigenous HACC issues to the attention of policy makers.

The implications of the role of HACC workers in relation to palliative care are discussed in Section 6.8.

6.5 Aboriginal health workers (AHWs)

AHWs work for AMSs, community clinics, community health centres and in some cases, in hospitals as ALOs. Their roles vary from State to State. Many Community Health AHWs undertake health education and disease prevention; in some AMSs and community clinics they undertake community liaison and patient transport roles; and in some areas they have clinical roles.

In remote areas, AHWs, together with clinic doctors and nurses, provide the only palliative care services available. Fried (2000) (209f) examines the role of AWHs in palliative care in Central Australia in some detail, outlining the broad scope of their role and the complexity of cultural issues they face. In some towns Aboriginal health workers from the AMS provide an informal (and untrained) palliative care role, often in their own time as AMS hours are 9.00 – 5.00, five days per week.

Many AHWs, especially those in remote communities, spoke of the huge personal cost involved in their work. For many, nursing Aboriginal clients is like nursing their extended family. Due to the high number of deaths, there is insufficient time to deal with each death as there are still other clients to look after. This was clearly culturally, spiritually and emotionally very difficult for these workers.

Many coordinators spoke of the need for additional resources to backfill positions so that AHWs could take the emotional and cultural leave they needed. The coordinator of a social and emotional well-being program suggested:

Recently four clients died and it would be great for the program to be structured so the worker could take leave – to backfill positions. It's very stressful to be providing emotional support to client and family as well as coordinate the requirements of other chronically ill patients.

In some communities there are quite large numbers of trained health workers who choose not to work in this role because of disillusionment or in some cases because of difficult cultural issues.

Health workers in remote areas reported feeling unsupported and overworked with regional staff not understanding what it is like for remote area workers.

6.5.1 The need for AHWs in palliative care

The need for trained Aboriginal and Torres Strait Islander staff to work in palliative care was repeated again and again by community members and AMS staff. AHW training needs to include a palliative care component (see Chapter 7). Funding is needed to employ and broker out trained workers as needed (see below).

In areas where traditional values are held and 'blame' is an issue, some have suggested that AHWs from outside the area should be employed. Others have argued for local AHW training so that people can work in their own communities. Fried (2000) has also canvassed the idea of providing some training to older Aboriginal people living in the remote communities to increase the capacity of communities to provide personal care. Such improved capacity may reduce the personal care aspect of the role that AHWs and nurses find themselves filling.

6.5.2 Some models of employment

Community members and AMSs suggested various models for employment of trained palliative care workers. It was widely suggested that they should not work exclusively for one organisation, nor exclusively in palliative care. Some suggested regionally based staff.

It would be good to have a palliative care AHW on staff who could work across the whole of western Sydney. They could be based in the AMS to help them keep the link with the community and the support they would need, but they could work with both the palliative care services. They don't need to be especially highly trained as long as they can work in partnership with the palliative care nurses. They should go to home visits with nurses. [AMS]

Health workers suggested that a palliative care trained health worker could work throughout the sub-district or even the region, and could possibly be employed by the division of GPs, with their services brokered out to the palliative care team, hospice, Homecare and the ACAT, etc. It is especially important to have Aboriginal workers present at the time of client assessment and early in the development of a relationship.

AMS staff in one area of the Northern Territory commented that it was vital for the local palliative care team to include ALO's and suggested that a male and female Aboriginal health worker should work with the palliative care team but be physically located in an Aboriginal organisation such as an ACCHS so they would not be working in isolation.

6.6 The need for cultural and linguistic interpreters

There is a notable lack of interpreters and interpreter services. It appears more likely that you will be able to get an interpreter if you speak a foreign language than if you speak an Indigenous Australian language. There is a desperate need for trained interpreters in places such as Perth and Adelaide and also in many remote areas.

6.7 Other Aboriginal and Torres Strait Islander health professionals

Very few Aboriginal and Torres Strait Islander nurses, doctors, psychologists and social workers are involved in palliative care. Strategies to raise the awareness of these groups and to solicit their input into the development of culturally appropriate practice should be pursued through their professional associations (eg CATSIN and AIDA).

6.8 Findings and recommendations

The findings about workforce issues are supported by the recommendations of a recent report into Breast Cancer Screening Diagnosis Treatment and Care for Aboriginal Women and Torres Strait Islander Women in Queensland – (Kirk, McMichael *et al.* 2000) which state:

- initiatives of government and non-government organisations need to be supported, eg the Queensland Health Indigenous Workforce Management Strategy, to increase the number of Aboriginal women and Torres Strait Islander women employed in cancer services, including screening, management and treatment, palliative care and support services to increase community trust and acceptability;
- the training of Aboriginal and Torres Strait Islander health workers should be promoted and supported, especially in rural and remote areas, in counselling, domiciliary and palliative care; and
- the number of Aboriginal and Torres Strait Islander health workers employed in palliative care and domiciliary care services should be increased.

6.8.1 Aboriginal and Torres Strait Islander staff in palliative care

Aboriginal and Torres Strait Islander health professionals and community members spoke about how important it is ‘*to have a black face*’ present (ie to have Aboriginal and/or Torres Strait Islander workers). It is very important that home-based services (and doctors making referrals to palliative care services) have trained Indigenous staff and/or buy in the services of such staff for advice and liaison.

Employment of Aboriginal and Torres Strait Islander staff would go a long way towards developing relationships between mainstream service providers and the community and would assist in the development of culturally appropriate services. It is important to ensure that Aboriginal and Torres Strait Islander staff working in this area are not isolated in mainstream services. It may be more appropriate to locate them in, or share them with, an Indigenous health service.

Where there is a significant Aboriginal and Torres Strait Islander population, trained Indigenous palliative care workers are needed either as full-time palliative care workers or to undertake additional duties. How these positions are funded should not necessarily affect where they are based, which would depend on the local situation. The following have been suggested:

- hospital ALOs (with AHW and palliative care qualifications);
- AMS-based AHWs who may be brokered out to other providers;
- AHWs based with a palliative care service; or
- Community Health based AHWs.

They could be regional workers, working throughout a health district with a number of service providers (mainstream and Indigenous), or they may be community-based, or located with service providers.

Two sorts of roles are needed: development and promotion roles to improve existing services; and more hands-on or face to face roles dealing with cultural and/or medical advocacy. Sample duty statements for these roles are given in Appendix 14.

There is a need for medically trained Aboriginal and Torres Strait Islander advocates (such as AHWs, enrolled nurses, registered nurses) to be employed by hospitals, health services and/or brokered in by palliative care services.

It is important that, wherever they are based, they should not be isolated from other Aboriginal and Torres Strait Islander workers and they should be professionally supported and supervised. Part of that support should include provision of interpreter services where necessary. Local Indigenous and palliative care service providers should be encouraged to work together to find the best local solution.

6.8.2 Implications in relation to HACC workers

- The skill and knowledge of HACC workers in delivering care to palliative care clients should be acknowledged and they should receive appropriate training and counselling.
- Funding barriers to the involvement of these workers in palliative care should be removed.
- The task of involving trained Aboriginal and Torres Strait Islander workers in palliative care may be more complex than getting Aboriginal and Torres Strait Islander workers involved in HACC programs, but the HACC model may offer some lessons.

6.8.3 Implications in relation to ALOs

- ALOs should be more actively involved in discharge planning
- Job descriptions, workloads, staffing levels, working conditions and qualifications should be examined to prevent exploitation of these workers and to ensure that Aboriginal and Torres Strait Islander clients receive the best service possible.
- In some places the demarcation between the hospital ALO and the community based AHW is not clear and causes problems. Increasing ALO involvement in palliative care would require some clarification of these roles. Local rather than global solutions would be appropriate.
- ALOs should be better supported through formal supervision and emotional or counselling support.
- If ALOs were to be more involved in palliative care support and liaison roles, then more would need to be employed or they would need to work more hours; they should also receive some medical training (AHW, EN or RN), because of the need for medical advocacy, as well as palliative care training.
- All ALOs should receive basic training in the nature of palliative care and the services available in the area.

6.8.4 Implications in relation to traditional healers

The use of traditional healers is regarded as Aboriginal and Torres Strait Islander 'business'. We were advised that it would not be appropriate to try to integrate these 'service providers' into the health system. They are part of a complex cultural and social system which may be endangered by trying to co-opt services into the western context.

Policy makers and service providers should be aware of the work of these healers and facilitate access to them when necessary. Funding might be supplied for fares and/or brokering in these services if needed. Consultation with these healers is usually a family matter. Palliative care service providers should support the family in consulting them if needed. AMS and other Aboriginal and Torres Strait Islander community organisations may have their own arrangements to facilitate access to traditional healers.

Traditional healers should be seen as an important adjunct to palliative care services where families want to have them involved. Funds should be available for use in the event that facilitation of access to the healers requires it.

6.8.5 Language and culture interpreters

All palliative care services should have the capacity to engage the services of language interpreters where the family involved does not speak English. Funding is needed for brokering in these services and in some places may be needed to establish them (eg a service offering various Aboriginal languages in Perth). These interpreters will require the same orientation as cultural advocates and should receive supported debriefing as part of their engagement (see further Chapter 3, Sections 3.2.8 and 3.3.2).

All palliative care teams should have the capacity (service delivery design and resources) to engage cultural advocates for their clients. Cultural advocates need orientation in the objectives and methods of palliative care (especially in respect for the individual's wishes) as well as cultural awareness training (in respect of the mainstream medical culture in which they will be working). Cultural advocates should receive supported debriefing as part of their engagement.

6.8.6 Other Indigenous health professionals

Strategies to raise the awareness of Aboriginal and Torres Strait Islander nurses, doctors, psychologists and social workers and to solicit their input into the development and delivery of culturally appropriate practice should be pursued through their professional associations (eg CATSIN and AIDA).

Training issues are discussed in Chapter 7.

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Chapter 7

Information, education and training



Clients at home – there are no support services for them. Some people are asking ‘What about our Health Workers? Why aren’t they trained in this area?’ – then we have to explain to them why they can’t come in. We need Indigenous workers in the palliative care team who can go out into the community and be there ‘hands on’ in the homes. One old lady didn’t have a drink for 24 hours because the family was too frightened to give her a drink because they thought she would choke. They didn’t have a sucker in the house – no one would know how to use it. [Queensland ALO]

7.1 Providing Information to the Indigenous community at large

7.1.1 ‘People don’t know about palliative care’

In the interviews we conducted most Indigenous people had never heard of palliative care and did not know about palliative care services. This applied as much to health workers, HACC and CAACP workers as to the general public. Some hospital ALOs do not know of community based services.

Most mainstream palliative care services have simple brochures about their services, however these were often not available in the foyer of the services (either community health centre or hospital information stands). The information is not available in AMS waiting rooms. At least one service provider we spoke with had a policy of explaining its brochure face to face and so did not make copies freely available.

People generally don’t consider palliative care until they need it, however palliative care services should make their leaflets more widely available in health information outlets and in Indigenous health and carer service centres. Copies should be available to Indigenous service providers.

In the Northern Territory, it was suggested by one person that promoting palliative care to the broad community could have a negative effect as death was the last thing people wanted to hear about.

When people have to go to Adelaide for tests they know it is serious and you see them give up [HACC Worker]

However in several places people pointed out that other issues, such as incontinence, used not to be spoken about, but now after successful strategies there was much more awareness.

It is important to explain that palliation is about relieving symptoms.

7.1.2 Existing information on palliative care for Aboriginal and Torres Strait Islander audiences

We did not discover any Indigenous-specific general information brochures about palliative care. There were four examples of information about palliative care that were specifically targeted to or prepared for Aboriginal and or Torres Strait Islander audiences.

1. A poster produced by the South Australian Palliative Care Council. The only people who spoke about this poster were service providers, not community members. The comments we received about it were that while it was colourful, it was not very informative and ‘...if you wanted to actually find out what it was about you would have to stand up and go right up to it to read it which might be embarrassing.’ We were told the South Australian Palliative Care Council has undertaken its own studies on the effectiveness of this poster, but the results are not yet available.
2. The Alice Springs Central Australian Palliative Care Service has a promotional poster, developed from a set of four promotional paintings by four Aboriginal artists representing major language groups of the region. They found the poster worked well in conveying the message in Alice Springs but not so well in other regional centres because it was not relevant to the Aboriginal language groups in those regions.
3. *Bessie’s Story* (Lowe and Floyd 1998), is a small booklet about palliative care for remote communities which has a limited distribution in the region for which it was developed.
4. A booklet from the Indigenous Carers’ Kit produced by the Australian Government Department of Health and Ageing was mentioned to us as being an important source of information about palliative care. This is a general aid for carers, but is not specific to palliative care and does not list palliative care services.

Although most people said that they thought ‘word of mouth’ information would be most effective, it was also suggested that simple information leaflets should be available to Indigenous clients and that it would be good to have an ‘Indigenous version’ printed, using the Aboriginal (or Torres Strait Islander) flag or another design.

An AMS in a remote community said ‘*Written information needs to be in local language with lots of pictures. Posters don’t convey education.*’ Others suggested simple English leaflets which give information about:

- who is eligible;
- what palliative care can offer;
- where you get it and what it costs;
- what happens next [steps]; and
- what happens if you don’t take tablets.

In some states (such as South Australia) there are booklets in many languages yet there are none specifically for Aboriginal people.

There is a need to explain to Aboriginal and Torres Strait Islander peoples what palliative care is – that it does not only mean a hospice, aged care facility or nursing home and that it is not only for cancer. If there is no fee that should be made clear as there are great misunderstandings about costs.

7.1.3 Word of mouth information

Overwhelmingly, Indigenous people said that the only effective way to spread information about palliative care was by ‘word of mouth’. They also suggest that such strategies should be backed up by written information (preferably with an Indigenous cover design or logo) which would usually only be required once people were aware that they had a need.

The implications are twofold: there is a need to develop ‘word of mouth’ strategies and medical referral needs to be supported by appropriate information materials.

‘Word of mouth’ communication will most likely occur through:

- people who have used these services mentioning it to others;
- Aboriginal and/or Torres Strait Islander health and care workers who are aware of palliative care services passing on information to potential users of these services as they come into contact with them; and
- medical referrals supported by Indigenous liaison staff or cultural advocates who are aware of palliative care services.

‘Word of mouth’ strategies could be implemented by:

- providing opportunities for Indigenous people with experience of palliative care services to tell their story;
- providing opportunities for people to find out about services (eg open days); and
- providing training and information for AHWs, ALOs and Indigenous HACC workers.

7.1.4 Telling stories of good service delivery

When you get to know each other the links are stronger – be very supportive and approachable and always follow up with clients who go back into that community – the community then gets a better level of care. It [information] all starts with individuals and then goes to groups and then the community benefits. [ALO, Queensland]

A number of community members suggested that videos could be shown on a loop in the foyer of AMSs. Some suggested creating opportunities for people to hear the stories of others, for example by placing media items in the Indigenous or local press (especially during palliative care week) and/or producing videos. In Mount Isa an article appeared in the local paper when the Indigenous palliative care worker was appointed and that was why many members of the community knew about palliative care.

7.1.5 Information days and ‘yarning’ sessions

Information days or gatherings for community leaders, elders, and health and care workers are effective. Two hospices (one of which also provides outpatient clinics and works closely with a community based team) successfully held information sessions or open days. We heard about these from community members who had attended and they were clearly valuable to these people who later used these services. In both cases the local ALO had made the arrangements. Involving community opinion leaders was clearly important in one case. Information days may be easier for facility-based care services to arrange, however it should be noted that many people we spoke with who had had experience of palliative care were happy to speak about their experience and some may be willing to take part. In the Northern

Territory one person suggested that informing Aboriginal church leaders in the region might be useful. In Queensland ‘yarning’ sessions were suggested:

Black fellas and forms don't get on. Bits of paper won't be read. The best way for passing on information is by 'yarning' in an informal way. In [] have set up a women's group which meets once a month as an opportunity for sharing information and airing views – they work out what they want and how they will go about getting it. Aboriginal health worker comes along and brings latest health information.

7.1.6 Informing key Indigenous health and care workers

As explored in Chapter 6, Sections 6.3-6.5, HACC workers, AHWs and ALOs are very likely to come into contact with people who require palliative care services. People in these roles are well placed to learn about palliative care and are also members of the community, likely to share information with family and friends. They are likely to be the main source of ‘word of mouth’ information.

Many of the health workers we spoke with thought that undergraduate AHW (Primary Health Care Certificate) and Aged Care Certificate courses should include sections on palliative care that would cover:

- ‘what is palliative care?’;
- what sorts of services and benefits palliative care can offer and how cultural sensitivities might be accommodated;
- how these services can be accessed; and
- what sorts of services exist in the State and region.

Where possible, the courses should present opportunities for AHWs and Indigenous aged care students to meet with palliative care service providers.

For workers who have already graduated, palliative care information and awareness programs should be developed. These might include:

- local service providers identifying and making contact with these workers and providing in-service training, information sessions and work experience opportunities;
- publishing articles in journals such as the *Aboriginal and Islander Health Worker Journal*; and
- developing mailing lists and networks of ALOs, AHWs (in both AMS and State government health centres), or using existing networks such as the Indigenous HACC reference group, to provide information about palliative care.

An ALO in Queensland suggested appointing an ALO as a resource person to develop awareness in the community and the hospital system.

In the short term, until undergraduate training programs take effect, information strategies targeting ALOs, HACC workers and AHWs should be developed. This might include the development of networks and newsletters and using existing associations or journals. Locally run information or training sessions would be appropriate.

7.1.7 Volunteer training

Strategies to inform Indigenous communities might also include offering volunteer training programs in venues and formats that would appeal (see below in Section 7.8).

7.2 Information for Indigenous clients

Indigenous palliative care clients and their families have special information needs (see Chapter 3 which outlines some of the socio-economic and cultural contexts). The underlying issues which give rise to these special needs include:

- cross cultural communication difficulties;
- literacy and education levels;
- difficulties in understanding medical terminology;
- lack of capacity to source information independently; and
- feeling uncomfortable about asking questions or asking for clarification, due to feeling intimidated or 'shamed'.

Indigenous people who had experienced palliative care consistently said that they had needed more information, earlier. In general the information needs identified included:

- Being supported when being told about the life limiting nature of the illness and the nature of palliative care:

My sister was diagnosed in December and died in August. We were not prepared for what we were in for. It would have been good to have had an Aboriginal person at the Cancer Clinic. There is an ALO at the hospital but not at the clinic. [Community member, NSW] (This woman was not introduced to the palliative care service until her sister was actually dying, despite having been diagnosed 7-8 months earlier and having been treated with radio- and chemotherapy. This story does not accord with what the palliative care service claims to be their practice.)

A health worker said it is important the patient has someone with them when the doctor tells them about their sickness. One client was carefully told by a doctor, the registrar, nurses, but still did not understand until the health worker talked to her. [Queensland]

- Written information about services available at that time, presented in a way that Aboriginal and Torres Strait Islander people can understand and relate to:

Don't know where to go – for example for modifications – one family got things done thinking palliative care would pay for it, but that didn't happen. People are not accessing respite. They don't know about having access to equipment like commodes – wives are carrying their husband to the toilet. Sometimes people are too ashamed to ask. Will we have to pay for this? We don't have the money. Even when I do home visits I have ladies who will have been up since 5am getting their house cleaned for the visit. Still that perception they have to clean the house. [ALO]

- Written information about the nature of palliative care, the likely course of an illness, the process of death, carer issues, legal and administrative issues to be considered, information about grief and loss, etc:

It would be really good if there was a booklet that covered what to expect – what to expect at the time of death – and there are also things that you don't know, like what to do after a person dies – where you can get support, where you can get help with a funeral, who you need to contact – like the tax office, the electoral office etc. [community member]

- Information specific to their situation at any given time, presented in such a way as can be understood, or provided with appropriate advocacy and interpretation. This requires the development of an ongoing and trusting relationship where service providers give information and reassurance, and continually check that the information has been understood.

Being able to meet these information needs will require different solutions in different settings, including:

- Language interpreters;
- Service providers being prepared to spend the time to check that people have understood. Training and guidelines in cross cultural communication should be developed for mainstream service providers;
- Cultural and medical interpreters and advocates. Mainstream service providers should be accompanied where possible and the client and service provider should have the services of a cultural advocate available if needed;
- Preparation of general literature for an Indigenous audience. For example, one of the most useful booklets that we came across was *Palliative Caring at Home* produced by Palliative Care WA Inc, Silver Chain and the Cancer Foundation of Western Australia¹. It is a small and comprehensive booklet which explains palliative care and covers the practical issues involved in caring for the patient at home. The booklet includes contact numbers of a range of organisations in Western Australia (including health regions outside of Perth), that the carer may need to contact, including where to get equipment, counsellors, resources and more information. This is a very practical booklet which closely matches the sorts of information which Indigenous people said that they wanted.

It should be a high priority for this booklet to be reviewed and edited for an Indigenous audience. The language is plain and should not require substantial editing. Additional information about the legal situation regarding reporting of death, how long the deceased can be kept at home and a section on what to do if the patient should end up on hospital would also be useful. The booklet should have a cover that will appeal to an Indigenous audience and should include State specific information about palliative care services and Indigenous support services. It may also be appropriate to produce a picture version for remote communities where literacy rates are low.

7.3 Information exchange between mainstream and Indigenous health care providers

Our research identified the need for better communication between mainstream and Indigenous health providers so that positive changes can take place and to ensure that Indigenous people can access the palliative care services they need.

¹ This booklet was adapted from the South Australian booklet *Palliative Caring at Home* prepared by the Palliative Care Council of South Australia.

Most palliative care services had little or no knowledge of Indigenous services and no contact lists for services such as Indigenous home care or HACC services, the Community Options Program, AMSs or other Indigenous groups or organisations in their regions.

Palliative care services need to have this information not only so they can provide it to Indigenous clients, but in order to begin a dialogue with these services. This project's Newsletter no.3 outlined ways that service providers and community organisations could begin such a dialogue.

A dialogue is also needed at senior policy level, between palliative care policy makers and Aboriginal health policy makers at State and Australian Government levels.

7.4 Education and training programs

7.4.1 Introduction

Our brief required us to identify available palliative care training and its relevance to Indigenous palliative care service provision. The following areas were explored:

- What palliative care courses are available for nurses, especially community nurses and remote area nurses? Is palliative care a standard part of nursing training? If not, how do nurses find training in this area? Where is it offered?
- What sort of cross cultural awareness training (or Aboriginal and or Torres Strait Islander cultural issues training) is available for nurses and where is it offered?
- What sort of information exists about Aboriginal health worker training and palliative care components of it?

Identifying the palliative care training available (except at post-graduate level) is not easy as there are no comprehensive listings. It is hard to tell which courses may include some elements of palliative care because course descriptions, even of relevant courses, often do not include the term 'palliative care' but use other terminology. As a result of many telephone calls, emails, internet searches and literature searches, we identified the training opportunities at various levels outlined in the following sections.

7.4.2 Tertiary training

Information from the Royal College of Nursing and curriculum searches on the internet revealed that, in general, palliative care training is usually available only for nurses at post-graduate level. For instance at La Trobe University, palliative care can be taken as a subject in a post graduate diploma or in varying degrees of specialisation as a graduate certificate, post graduate diploma, a master's degree or at doctorate level.

Flinders University has recently added a graduate diploma course to its existing post-graduate program (Graduate Certificate, Master of Palliative Care and Master of Science (Palliative Care)), beginning in 2002. This will allow students to complete the diploma after two years' part time study. Numerous short courses are also offered by the International Institute of Hospice Studies (allied to Flinders University) for registered nurses, enrolled nurses and care workers.²

² Other courses include short courses held at the Peter MacCallum Cancer Institute and a graduate diploma at Melbourne University (personal communication Cathie Pogott).

In the Northern Territory palliative care services based in Darwin and Alice Springs offer education to health practitioners in community and hospital settings, as well as to clients, carers and families in urban Darwin, Alice Springs and rural and remote settings. The urban program concentrates on nursing homes, hostels, hospitals, community health centres, families and HACC workers. The rural team provides education for the rural hospitals and remote community health centres as well as aged care facilities and HACC workers.

In 1999 an agreement was made between the Territory Palliative Care Service and the Northern Territory University (NTU) to transfer the main part of the training course into the tertiary sector at the NTU as part of undergraduate nursing training. The course includes topics relating to Indigenous palliative care and service delivery to rural and remote regions, as well as more typical training in management of symptoms, pharmacology, grief and bereavement, occupational therapy, pastoral care and other therapies.

Other training providers include the Mercy Health Service based in Albury which has developed a VET-accredited training program with three strands for:

- community peers (volunteers);
- enrolled nurses and allied health workers (eg social workers); and
- registered nurses.

Apparently none of these courses are directly suitable for HACC or Health Workers although some of their elements would be. The courses were developed in order to shift the focus of the medical practitioner away from medical provision to focus on the person.³

Meadowbank TAFE has developed a training program for enrolled nurses.

7.4.3 Palliative care training in the mainstream system

Our interviews with mainstream palliative care providers indicate that the level of palliative care training of nurses providing these services is not high. Many of the nurses we spoke with had little or no specific training. Palliative care services are set up with one or two CNCs who usually have postgraduate qualifications in palliative care and who provide advice to generalist nurses who do most of the hands-on work. Some nursing services provide their own short courses on palliative care, such as the five day training program which is run by the RDNS in Adelaide once or twice year for its generalist staff. Most nursing homes do not have palliative care trained staff. It would be very rare to find a nurse trained in palliative care in a remote clinic setting.

Most of our respondents commented that there were not enough trained staff, not enough training programs and not enough money to release people for training.

7.4.4 Training in palliative care for Aboriginal and Torres Strait Islander health workers

Various Aboriginal community-controlled health services across Australia provide accredited vocational training for Aboriginal and Torres Strait Islander health workers.

The mainstream Kimberley/Pilbara Palliative Care Network has *'liaised with the Aboriginal health workers school in Broome to increase palliative care content in their course'*.

³ Pers Com Camilla Rowland.

Bachelor College (a major Northern Territory Aboriginal College) now offers an undergraduate, post graduate and certificate course in palliative care which has been developed by the Top End Palliative Care team.

The Education Centre of the Cancer Foundation of Western Australia (Cottage Hospice) has run a training program for care aides and personal carers from Marr Mooditj⁴ and are holding discussions regarding the development of post graduate courses.

Aboriginal health worker training has recently been the subject of a review (Health Workforce Section OATSHI):

Currently a health training package is being developed with funding through the Australian National Training Authority. The expected outcomes of this work include the identification of a framework for skills based on competency standards, improved career mobility, and a flexible and efficient vocational training framework.

The prospect of a new national framework of competency-based health qualifications offers some significant opportunities and issues for these training providers.

[<http://www.health.gov.au/oatsih/pubs/trainpk.htm>]

7.4.5 On-line training and tele-health

On-line education in palliative care was reviewed in Palliative Care Australia Summer Edition 2001 (Education in Palliative Care). The review did not reveal many specific on-line palliative care courses, though the point was made that most universities tend to design courses for flexible delivery. The article mentions the Australian Catholic University's new on-line units (two units) in its post-graduate course.

A palliative care educator (rural and remote areas) at the Cancer Foundation of Western Australia is based at Cottage Hospice. This Education Centre recently introduced tele-health to provide regular palliative care education sessions, however until now has done no specific training for Indigenous palliative care. The educator believes they could have a role working alongside or with the AMS to develop an appropriate training package. The tele-health service is mostly accessed by medical staff in more remote areas who have no other access to training.

The Royal College of Nursing developed a Distance Education Palliative Care course for enrolled and registered nurses which was run once. The College believes this course could be successfully modified for delivery to Indigenous health workers.

7.4.6 Volunteer training

Various courses are available for volunteer carers, though we have not identified any which are specifically designed to be culturally appropriate for Indigenous carers.

One of the roles of the mainstream Kimberley/Pilbara Palliative Care Network is to coordinate education for the region as a priority at both the community and professional levels. They have conducted community forums on death and dying, held talks for community groups, and organised displays, newspaper articles, radio sessions, visits to Aboriginal communities and participation at regional aged care workshops.

⁴ Marr Mooditj is a major provider of Health Worker training in Perth.

7.4.7 Training for service providers in delivery of palliative care to Indigenous clients

We have not identified any of this type of training. Many nursing courses and palliative care courses contain some elements of cross cultural training however we understand that these are not intensive and do not specifically deal with Indigenous issues. The Australian Government funded the National Guidelines project will provide some materials for this purpose. Mungabareena Aboriginal Corporation and Wodonga TAFE, in association with Mercy Health Service, are working together to produce national guidelines for service providers who provide palliative care to Aboriginal and Torres Strait Islander peoples.

The overall aim of this project is to help palliative care professionals to provide culturally appropriate palliative care to Indigenous peoples and communities. As well as the national guidelines, the project will produce a national education and training resource, and recommendations on how the guidelines and education and training resource can be implemented. The education and training devised will be nationally accredited and will support the philosophy and principles of palliative care practice. The project will use the findings of this study and other research.

7.5 Training Indigenous staff

There are very few Indigenous staff formally working in palliative care. These include one AHW in Mount Isa and one in the Top End Palliative Care Service. There is one ALO in the Domiciliary Care service in Adelaide, whose work is not exclusively with palliative care clients. There is one Indigenous nurse (Indigenous Clinical Advisory Nurse) in Royal Perth Hospital who works with palliative clients, though not exclusively. The work of other Indigenous staff who work informally or more peripherally with palliative care clients is described in Chapter 6. No training programs are currently available for these staff.

Given the enormous stresses communities are under due to their primary health status and because of the impact of sudden death, education and training about palliative care may not be a high priority for some Indigenous health providers. While the need for trained Indigenous staff in this area is recognised, it is not the highest priority. Palliative care was not identified in any of the regional plans prepared in relation to the Primary Health Care Access Program (PHCAP). One informant who had been involved in the development of such a regional plan said that was not because there were no needs in relation to palliative care, but that '*palliative care was not in people's consciousness*', and so was never considered.

7.5.1 Post graduate training for AHWs

There is clearly a need to involve Indigenous people in palliative care service delivery. Indigenous people should be employed in various ways, including:

- as development staff (to monitor and improve the services of palliative care providers such as domiciliary nursing services, hospices etc.);
- to accompany home visits to provide cultural and medical advocacy;
- to liaise between AMSs and palliative care service providers;
- to assist service providers to coach families in providing care at home; and
- to support families through grief and loss in a number of ways, including assisting with funeral preparation.

In order to perform these roles Indigenous staff need training in aspects of palliative care and in grief and loss counselling. Discussions with some AHW education providers raised the possibility that the most appropriate way to accomplish this might be to develop a post graduate Certificate in Palliative Care and or a post graduate Certificate in Mental Health (Palliative Care).

Some work has already begun at an undergraduate level. The Cancer Foundation of Western Australia (Cottage Hospice) Education Centre has run a training program for care aides and personal carers from Marr Mooditj.⁵ Both Marr Mooditj and the Education Centre thought that this had been very successful and discussions have been held about working to:

- integrate palliative care component into the Health Worker Certificate 4 training;
- develop a post graduate diploma in palliative care in health worker training; and
- integrate a palliative care/bereavement/grief and loss component into the Diploma in Aboriginal Mental Health or develop a separate diploma focusing on this.

A number of people spoke of the importance of trying to deliver AHW training locally so that local people can be trained to work in their own community. An Aboriginal medical service representative said that:

Any palliative care training needs to be local because we want to ensure that Aboriginal people are trained to be able to deliver services. There is such a high turnover of non-Indigenous staff, by employing and training local people, the project won't stop. [remote town in Western Australia]

This was suggested even though it appears that in some areas employing AHWs from outside the community may be important in avoiding blame and payback. Fried (Fried 2000) also writes of the importance of training local older people in their own setting.

7.5.2 Need for more Indigenous nurses

Many people spoke of the need to have 'more black faces' in hospitals and for medical advocacy – ie, someone who is culturally attuned and who can also understand the medical issues involved. Every effort should be made to encourage and fund the training of Indigenous nurses.

7.5.3 Qualifications and training for ALOs

The findings reported in Chapter 6 suggest that the role and qualifications of ALOs should be examined to ensure that they have appropriate skills, working hours and support to undertake the work asked of them. All ALOs, whether they have a social work background or an AHW qualification, should have an understanding of palliative care (see above Sections 7.1 and 7.2). If these positions are to be part of or brokered into palliative care services, then they need adequate training in palliative care and relevant training to enable medical and cultural advocacy.

7.5.4 Aids in nursing (AIN) training

Aids in nursing are often employed in nursing homes. The director of an Aboriginal nursing home suggested that AIN training should also include a component on palliative care. This would raise staff awareness of issues and may equip these staff to be more supportive to family and patients.

⁵ Marr Mooditj is a major provider of health worker training in Perth.

7.5.5 HACC workers

Palliative care should be included in Certificate 3 courses for HACC workers.

7.5.6 Psychologists and grief and loss stuff

The need for trained Indigenous psychologists and counsellors is discussed above in Chapter 5, Section 5.5 (*Counselling and Bereavement Care*). Consideration should be given to providing special scholarships for Aboriginal and Torres Strait Islander people to undertake psychology degrees. The AHW Mental Health Diploma should also be reviewed to include a component on palliative care and bereavement.

7.5.7 Cultural and/or linguistic interpreters

Cultural or linguistic interpreters should undertake orientation training in the principles of palliative care and the importance of respecting and reporting individuals' wishes in the palliative care context, irrespective of the cultural norm.

7.5.8 In-service and other training measures

Palliative care units could explore opportunities for delivering in-service programs to AMSs and other relevant service organisations.

For example, the palliative care unit at a base hospital in Queensland called a meeting with local Indigenous health workers and asked them to complete a questionnaire about how they could improve their service. They requested education specifically for Indigenous workers. The hospital is about to begin a program of getting the email addresses of the Indigenous health workers and encouraging them to email requests for information. The CNC's response will be emailed back to all health workers.

Given that curriculum development takes time, it may be useful to examine existing courses, such as the TAFE Volunteer training programs or the five day training programs in palliative care delivered by RDNS in Adelaide, to see if they would be appropriate (with or without modification) for AHWs or ALOs employed to work in palliative care.

7.6 Education and training for other health professionals

7.6.1 Education of GPs and medical specialists

The need for GP education about palliative care is well recognised. GP education programs should be encouraged and should be expanded to include: cultural awareness information or training about 'giving bad news'; the need for cultural advocates; and that assumptions about Indigenous people's wishes should be avoided.

We were often told that oncology specialists, renal specialists and others are not as aware or supportive of palliative care as they should be. These specialists would also benefit from training in how to 'break bad news' and how to involve cultural advocacy for clients and families at critical times. In remote areas there is a constant training need due to the high turnover of doctors.

All palliative care service providers thought there was a need to train general practitioners in palliative care, what it can offer, how it can be delivered and how it may be made suitable for Indigenous clients. The comment that '*GPs are not very available and not very skilled*' was made. Some GPs are very knowledgeable and skilled in palliative care, but these are in the minority. Palliative care educators say that when they run programs for GPs they are usually attended by those who have already had training: '*We are preaching to the converted.*'

One GP spoke about her work with Aboriginal clients: '*We do our own palliative care...*' GPs appear to be reluctant to use palliative care services and many do not have a good understanding of what is offered.

In particular, GPs need to be trained to offer a range of choices to all clients, rather than assume that Aboriginal people will not want to access mainstream services, and to seek out appropriate Aboriginal liaison support.

7.6.2 AMS Doctors

Like other GPs, many AMS doctors are generally uninformed about the nature and benefits of palliative care services. By their own admission they do not make use of these services (where they know of them) because of a belief that clients may not wish to use them. (see Chapter 4). GPs in general require information and training about palliative care and this special sub-group of GPs could be specifically targeted.

There are opportunities for OATSIH, NACCHO and the College of General Practice to work together to develop and provide training programs which inform GPs (and AMS doctors in particular) of the services and benefits of palliative care, to suggest strategies for working with palliative care service providers to deliver an integrated and sensitive service to Indigenous clients.

7.6.3 Nursing homes and aged care facilities

The findings reported in Chapter 5 point to the need for the development of strategies, including funding strategies, to encourage more in-service training and to facilitate the release of staff to undertake specialised palliative care training and cultural awareness training.

7.6.4 Community nurses

Generalist community nurses often provide services to palliative care clients, calling in a CNC only when necessary. All community nurses should undertake cultural awareness training specifically designed for people delivering services in the home. Community nurses should also have some palliative care training. They are in a unique position to identify clients in need.

7.6.5 General nurses

Undergraduate courses could include material to increase awareness of palliative care and cultural issues, and training in when palliative care specialists and cultural advocates should be called in.

7.6.6 Training for decision makers

An AMS staff member in the Northern Territory suggested that administrative staff also need training: *‘organisations can’t make management decisions relating to palliative care unless they understand about palliative care – organisations need to be resourced properly to address palliative care issues. If positions are unsupported staff will not be willing to stay.’*

7.6.7 Awareness for other Aboriginal and Torres Strait Islander health professionals

The peak organisations representing other Aboriginal and Torres Strait Islander health professionals such as nurses, psychologists, social workers and doctors should be engaged to assist in the information strategy.

7.7 Cultural awareness training

The major outcome of cultural awareness training should be to have service providers listen to what they are told and really hear it. Teaching people to develop the skills of listening and hearing is as important as cultural awareness. [community member in Perth]

7.7.1 Not enough cultural awareness training

Despite the fact that cultural awareness training is mandatory in many state health systems (eg New South Wales) the view of ALOs, community members and Aboriginal health workers is that it is very inadequate. The training is generally very superficial (sometimes only 15 minutes in a general induction program) and even where there are enough programs available, they are not taken up at adequate rates (for example, staff shortages may mean that people cannot be released from duties). In some places where additional training has been delivered (such as the ICU of a western Sydney hospital), improvements have been marked, with staff becoming far more accommodating of the needs of Aboriginal people at the time of death.

Training does not appear to be mandatory in some hospitals. The palliative care team in one Perth hospital were unaware of any specific cultural awareness programs, though they thought that most of their staff would have *‘picked up a day here or there’*.

High staff turnover is a major problem in many hospitals: *‘As soon as you get some staff trained they move on.’*

In hospitals in remote areas such as Kalgoorlie, a very high number of agency staff are used because of staff shortages and these are often foreign nurses who have received no Indigenous cultural awareness training at all.

One of the major problems however is that there is a very rapid turnover of staff. Most of the nurses at the hospital are agency staff and they are there on a short term basis. They all need additional training and they are not here long enough to develop experience. Many of the agency staff are from overseas – so they really need cultural awareness training. There is a need for better orientation for short term staff – a day’s training would be time well spent.
[local doctor]

Most home nursing service staff (eg Blue Care) have not had any cultural awareness training or have not had Indigenous-specific training. This is especially problematic when they are caring for clients in their own homes.

The perspective of an AMS in the Northern Territory is that palliative care team members need greater awareness and the ability to engage with the family so as to involve them in the care. Service providers also need to have ongoing interaction with cultural leaders in each local community, not just generalised 'awareness' courses.

7.7.2 Cultural blindness

Palliative care service providers need to acknowledge the difficulties inherent in cross cultural communication and take opportunities to develop awareness of their own attitudes and values and how these may differ from that of their clients.

The 'culture' which informs our thinking and world view includes our gender and many other aspects of our background, personal experience and professional socialisation. We become relatively blind to the ways in which our experience differs from that of others. The wider the 'cultural gap', the more likelihood there is of communicative distortion when we attempt to cross that gap. [(Fried 2000) p110]

Cultural awareness training is a first step. Cultural awareness training really needs to go beyond 'awareness' to deliver cognitive change resulting in changed behaviours and effective cross cultural practice.

7.7.3 Course intent and content

Generalised cultural awareness training is inadequate to equip palliative care workers for the cross cultural practice they engage in with both Aboriginal and Torres Strait Islander clients and other culturally and linguistically diverse groups.

Cultural awareness courses should be tailored for palliative care workers and should provide:

- a learning environment in which participants can candidly review their own beliefs, value systems and communication practices as a basis for acknowledging and accepting other world views;
- more information about Aboriginal and Torres Strait Islander death and end of life issues (ie a course especially developed for palliative care workers);
- more information about how to establish contact and build relationships with Indigenous organisations, communities and individuals;
- more about the limits and dangers of cross cultural communication, especially in the context of unequal power relationships (such as Indigenous versus non-Indigenous status, health system versus patient, expert versus family). Courses should emphasise that participants should be aware how little they know;
- emphasis on the cultural variations that may exist within an area or region. Some hospitals, such as Royal Perth, employ Indigenous people for three major Aboriginal cultural groupings, as well as Torres Strait Islanders; and
- resulting in cognitive change.

Generalised courses are often inadequate preparation for dealing with the particular culture of the area in which one is working, and especially with the complexities of communicating about end of life issues. An AMS perspective in the Northern Territory is that palliative care team members need greater awareness of local issues and an increased ability to engage with the family to involve the family in the care.

Courses should aim to improve competency in effective cross cultural practice. This will require the delivery of cognitive change, rather than mere 'awareness' Research into the competencies required for cross cultural practice and a review of the effectiveness of current cultural awareness training in health systems would be timely.

7.7.4 Context of cultural awareness training and worker exchange

Several AMSs suggested that cultural awareness training should take place in the local AMS or in an Aboriginal community organisation. It should take place on 'Aboriginal turf'. Opportunities for work placement (work experience) in Aboriginal health organisations should also be pursued.

7.7.5 Resources and skills available for training

Delivery of effective training for cross cultural practice requires adequate time and the service of a skilled trainer.

Aboriginality is not a training qualification *per se*. The task of leading people to a consciousness of their own beliefs and values – a starting point for beginning to understand the values and beliefs of others – requires considerable training. It is unfair and unrealistic to expect junior staff such as ALOs to attempt such a task unsupported by qualified trainers.

7.7.6 Cultural awareness and assertiveness training for Indigenous staff

Indigenous staff working in mainstream organisations may need some cultural awareness training to inform them of the social and cultural context in which they will operate.

In some areas, Indigenous staff also need cultural awareness training. For instance in Perth most of the Indigenous staff are Noongars, and need orientation for Wongi and Kimberley Indigenous cultures.

7.7.7 Not a substitute for Indigenous staff

Cultural awareness training should not be seen as a substitute for the employment or brokering in of Indigenous staff. Conversely, employment of Aboriginal liaison staff does not abrogate the need for cultural awareness training and cross cultural communication skill development. ALOs and AHWs are too often left to bear the burden of communicating complex western or medical concepts to Indigenous clients. All members of the team need to work together as a team to bridge the cultural divide.

7.8 Volunteers programs and support groups

7.8.1 The role of the volunteer

Nearly all home-based palliative care services and some residential palliative care units have volunteer programs. The role of volunteers ranges from the 'caring neighbour' role (keeping company, helping with transport, occasional shopping, and supportive listening) to a greater focus on bereavement care.

7.8.2 Coordination and training of volunteers

Most programs employ a full or part-time paid coordinator and offer training programs that range from 24 to 40 hours, given either in a week long block or for several hours a day over several weeks. Some training programs are conducted by TAFE. Most include information about the nature of palliative care, the course of death, the nature of grief and loss, reflective listening skills and occupational health and safety issues. Volunteers and their co-ordinators should have cultural awareness training.

7.8.3 Recruitment of volunteers

Recruitment of volunteers is usually done by advertising and screening. Some are recruited from experienced hospital based volunteers. None of the services we spoke with had recruited or aimed to recruit Indigenous volunteers.

7.8.4 Volunteer manuals

One volunteer group uses a *Volunteer Training Manual*, by P.A. Gallasch, which was developed and trialled as part of a national palliative care grant secured by the Murray Institute of TAFE. The manual does not include information about providing palliative care in a cross cultural environment.

Volunteer manuals need to be revised to include sections on working in cross cultural environments.

7.9 Aboriginal views about volunteers and support groups

Most of the community members we spoke with thought that it would be a good idea to have some community members 'trained up' so they could help. Some thought that support groups of people who had been through the experience would be more useful. Community members in a remote town in Western Australia were keen to develop such a support group, and the idea was also raised in Queensland and South Australia.

Some people thought that volunteers gave better care than nurses because they were more committed.

Only one person we spoke with had had a volunteer to assist her while she was looking after a dying family member. She had found it very useful, however after some months the volunteer had been unable to continue for personal reasons.

Few Aboriginal people would be able to volunteer in the same way as those who are generally involved in volunteer programs, who are in a position to volunteer their time free of charge. Most Aboriginal people need to work and have many family commitments already. There is also an underlying feeling that

people should not be asked to provide services for nothing and should be paid. Nevertheless, many community members expressed the view that *'it would be good to have some people trained up'*, because although they do not have 'free time' to enter into volunteering programs, the reality is that they often help out family and friends within their close knit community in a way that does not often occur in mainstream communities. Lack of access to vehicles and disposable income would limit the volunteer activities that could be undertaken. In Perth people said that they thought it would be good to develop a 'home visiting group'.

If attempts were to be made to recruit Aboriginal or Torres Strait Islander people into mainstream volunteering programs, 'word of mouth' would be the most effective approach to recruitment, and special attention would need to be paid to arranging a 'buddy system' for training programs so volunteers would not feel isolated in a largely non-Indigenous environment. Training courses may need to be modified in some areas to accommodate literacy and education levels of participants. There may be scope for Indigenous participants to educate their colleagues in Indigenous perspectives of care.

7.9.1 Informal volunteering

In the Torres Strait we spoke with a woman who had cared for three family members who had died from cancer. The informant works in an ancillary service at the hospital. No information or advice about palliative care is available on the island and because people know her interest they seek out her advice about what they can do, what sort of food can be eaten, and so on. She says the hospital is unaware that she provides this advice.

7.10 Findings and implications

Employment and training of Aboriginal and Torres Strait Islander staff to work in palliative care should be a central and immediate target at all levels. Palliative care services need to employ trained Aboriginal and/or Torres Strait Islander staff to assist in the development of their services. These positions are needed at State level (in government and/or in Palliative Care Associations) and in services in regions with high Aboriginal and Torres Strait Islander populations.

Awareness at policy level

Policy makers at State and Australian Government levels should be encouraged to consider and incorporate palliative care for Indigenous clients in policy and funding documents (eg State / Indigenous health partnerships, state strategic plans and OATSIH funding formulas). The challenge here is not only to raise awareness of policy makers about palliative care for Indigenous peoples but to do so in such a way as to ensure that local Aboriginal communities will be engaged in advising on their particular needs. Decision makers in ACCHS and State-run Aboriginal and Torres Strait Islander Health units must be specifically targeted. (See further Section 7.6.6).

7.10.1 Information for the community at large

Most Aboriginal and Torres Strait Islander people and Aboriginal and Torres Strait Islander service providers (AMSs, HACCs, CACP and AHLOs) are not aware of what palliative care is or what services might be available. Information strategies are needed which address these issues.

For community information, ‘word of mouth’ strategies are best and AHWs, ALOs and HAACC workers will be the key to the success of such strategies. Introduction of information about palliative care into undergraduate training programs for these workers will assist in the long run, and in the short term, other information strategies should be developed. Finding ways to encourage people to tell stories of good service, arranging information days and ‘yarning’ sessions were some of the strategies suggested to reach the community (see Section 7.1).

Communication strategies for Aboriginal and Torres Strait Islander communities and for decision makers working in Aboriginal and Torres Strait Islander health should be developed.

7.10.2 Information for Indigenous clients

Aboriginal and Torres Strait Islander community members who had experienced palliative care clearly identified the kinds of issues about which they wished they had received more information, and indicated that the earlier the information was available the better. As well as information about the range of services available (including Indigenous specific services), the clearest need was for the kind of information that has been provided in the *Palliative Caring at Home* booklets produced by the South Australian and Western Australian Palliative Care Associations (see Sections 7.1 and 7.2). These booklets could readily be reviewed and revised to meet this need.

7.10.3 Information exchange between mainstream and Indigenous health care providers

Mainstream and Indigenous health providers tend to work ‘in parallel’ and they often do not relate to each other. They may be unaware of how the other providers operate, what services they provide, and how they could work together (see Chapter 4, Sections 4.3 and Section 7.3 above). Initiatives which build relationships between all relevant service providers should be pursued.

Local planning workshops are needed so that Indigenous health and home care services can find out what palliative care services do, and vice versa, and then work out how best they can work together. Local colleges of GPs should be involved in these workshops.

There is a need to raise the profile of mainstream service providers in the Indigenous community, including naming specific individuals as contact people for Indigenous clients and services, so that relationships can be developed and so that people can get to first base in developing care planning. Such relationships currently do not exist in most places, however before partnerships can develop basic relationships need to be in place to establish a basis for trust (see further Chapter 5, Sections 5.4.2 and Section 7.3 above).

A number of protocols then need to be developed on a local and regional basis to allow adequate care planning to develop (eg see guidelines in Appendix 12).

7.10.4 Education and training programs

Lack of palliative care training

There is an urgent need for development and provision of training for Aboriginal health workers – for example, including a component in undergraduate courses; creating post graduate certificate courses in palliative care and in mental health and bereavement (see Section 7.5).

There is an urgent need for trained Indigenous psychologists and mental health workers to provide support or counselling in grief and loss (see Section 7.5).

7.10.5 Training for Indigenous staff

Indigenous health workers (Hospital ALOs, Aboriginal primary health workers and HACC workers) need training and awareness programs about palliative care and palliative care services in their State and their own region (see Chapter 6 and Section 7.4). Other Aboriginal and Torres Strait Islander health professionals including nurses, psychologists and doctors may also benefit from such programs.

The peak organisations representing Aboriginal and Torres Strait Islander health professionals such as nurses, psychologists, social workers and doctors should be engaged to assist in an information strategy (see further Section 7.6.7).

Aboriginal health worker undergraduate training needs a palliative care component to explain what palliative care is and to explain what services are available in each State. (see further Section 7.1.3).

Aboriginal and Torres Strait Islander community controlled health organisations (and other Aboriginal and Torres Strait Islander health services) need education about palliative care and its benefits, and how they can get help from palliative care specialists for their clients (see Section 7.6.2 and Chapter 4, Section 4.3.2).

There is a defined need for a post graduate Certificate in Palliative Care for health workers and a need for a component on grief and loss associated with palliative care in the Mental Health Certificate (see further Section 7.6.1/2).

7.10.6 Education and training for other health professionals

Education of medical practitioners and health services

Professional development curricula for GPs, nurse practitioners and registered nurses in the Aboriginal and Torres Strait Islander health sector need to include issues related to palliative and bereavement care. For GPs this could be facilitated through CME programs coordinated by professional colleges, and for nursing graduates, through the development of specific post graduate certificate level courses. A specific module on Indigenous issues in palliative and bereavement care should be included in undergraduate training curricula for all doctors and nurses as part of their education in Indigenous health.

Mainstream palliative care workers need specific cultural awareness training, tailored for palliative care workers, which will translate into effective cross cultural practice and competence. Cultural awareness courses for palliative care workers need to be revised to deal with issues of death and dying for Indigenous people and to provide safe learning environments where practitioners can review their own belief and value systems and communication practices. Professionals delivering care at home need special skills in developing relationships with the local Indigenous community and with individual clients. This is critical given the high frequency of late referral of Indigenous clients to palliative care (see further Section 7.7).

In the first instance, this education might look at basic issues of developing cross-cultural partnerships with Indigenous organisations in the community. Such education could be attended by both mainstream palliative care organisations and Aboriginal and Torres Strait Islander health services in each local region.

General practitioners (GPs) and specialist doctors may not be aware of palliative care services and the associated benefits to their patients. Education is needed to increase doctor awareness and encourage earlier referral to palliative care. Referral to palliative care does not have to mean that the GP stops caring for the patient (see Section 7.6.1 and Chapter 4, Section 4.3.2).

GP and AMS doctor education

It is extremely important that GPs who work with Aboriginal and Torres Strait Islander clients⁶ have the opportunity to learn more about palliative care and cultural issues surrounding death and dying. It is important that AMS doctors come to see palliative care as a special service which they can access for their clients and in which they can take a central role. It is suggested that a CME package (Continuing Medical Education) on these issues be developed for GPs. Assistance might be sought from the College of General Practitioners to sponsor such programs in areas of high Aboriginal and Torres Strait Islander population.

Professional awareness

Strategies aimed at government and community-controlled Aboriginal health services to develop the awareness of health professionals working in them (doctors, nurses and health workers) about palliative care are needed. These groups should be specifically targeted and included in programs such as GP palliative care education. The support of NACCHO, OATSIH, and bodies such as CATSIN and AIDA should be enlisted (see further Section 7.6).

7.10.7 Cultural awareness training

All palliative care workers and community nurses should have regular cultural awareness training and related work experience opportunities to develop competence in cross cultural communication. Cultural awareness training needs to be developed to deliver effective cross cultural communication and practice as well as to deal with issues specifically related to Indigenous death and dying. Cultural awareness training of hospital staff should be reviewed and improved, especially where large numbers of agency staff are used in areas of high Aboriginal and Torres Strait Islander population (see Chapter 7).

The effectiveness of cultural awareness training needs to be reviewed and competencies in cross cultural communication and service delivery developed and delivered (see Chapter 7).

7.10.8 Volunteer programs and support groups

A number of Aboriginal and Torres Strait Islander people spoke of their desire for support groups for families coping with the life limiting illness of a family member. Some were interested in becoming volunteers within their own communities. No mainstream volunteer programs have previously recruited within Indigenous communities. There is scope for these programs to be made more effective, however coordinators of volunteer programs would need cultural awareness training and guidance from Aboriginal and/or Torres Strait Islander advisors about recruiting within Indigenous communities (see further Section 7.9).

It appears that the sort of training available to volunteers could be easily adapted and upgraded for delivery to AHWs and enrolled nurses.

⁶ including those who work in ACCHS or AMSs, and those who work in regions with high Aboriginal and/or Torres Strait Islander populations.

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Chapter 8

Some aspects of good practice



8.1 Introduction

As outlined in Chapters 2 and 4, there are few, if any, Indigenous-specific palliative care services and Aboriginal peoples and Torres Strait Islanders have a low level of access to mainstream services. During the scoping phase and in the field work we sought to discover examples which might be considered to be good practice. We also heard from community members and service providers about the sorts of things that needed to make services more accessible and appropriate to Aboriginal and Torres Strait Islander people. These are described in Chapters 5-7.

In the course of our investigation we discovered aspects of practice which we considered to be innovative or 'good'. This chapter highlights some of these (without going over ground covered in previous chapters) and describes some models of service delivery.

8.2 Practice highlights

8.2.1 Palliative care provider as coach

In one palliative care service we found an approach that stood out as being exactly what many Aboriginal and Torres Strait Islander community members were asking for. Here the service providers viewed themselves as coaches for the family, providing them with training and support so that they could look after someone at home. They also provided specialist advice and coordinated other needed services (including access to residential facilities if required). This approach enables family members to feel they are in control of care.

8.2.2 Some key elements of good practice

As outlined in Chapter 5, key elements of good delivery of care include:

- early referral;
- cultural advocacy and brokerage;
- good communication and relationship development;
- clear coordination (e.g. everyone's role is clear);
- regular case management meetings, including cultural advocates;
- continuity of care; and
- flexibility and responsiveness which recognises individual needs.

Residential or in-patient palliative care

Aspects of good practice in relation to residential settings of palliative care (hospitals and hospices) are detailed in Chapter 5. See also Appendix 8 and Appendix 9.

Good practice opportunities in regions where passing away at home will present a cultural problem

The need for a comfortable and 'neutral' place where people can pass away that is readily accessible to family members, is discussed in Chapter 5, Section 5.3. Three key possibilities were raised:

- the development of care centres separate from hospitals where people and families could come for the terminal phase;
- in remote communities, a room and family accommodation near the clinic that could be used during the terminal phase; and
- public (or Aboriginal) housing authority to make a house available for the duration of the palliation when deemed necessary, so that appropriate care could be given, family members could stay and families would not have to vacate their own home after the death.

Behaviours

Community members appreciate the kind of behaviour and approach from palliative care service providers given in the following example:

Dr [] ... wanted to provide a better service and wanted the best for everybody. She wanted Aboriginal people to be able to exercise culture. She would sit on the floor, squat down under a tree. While she was working here she kept ALO's informed and would give us all a run down on that person. She attended funerals of patients. [ALO]

Bereavement

At one AMS, AHWs were actively involved in assisting families with practical issues at the time of death, for example, working with families to develop the 'order of service' and prepare eulogies. This process is an important and practical bereavement support activity which is currently not funded.

In South Australia one palliative care service provider had set up peer support groups as part of its bereavement program. Community members independently talked about the need for these groups (especially for men). Innovations and good practice in bereavement care are discussed further in Chapter 5, Section 5.5.

8.3 Staffing and training matters

The need for Aboriginal and Torres Strait Islander staff in palliative care services has been commented upon throughout this report. The study found only two mainstream palliative care services that employed an Aboriginal or Torres Strait Islander staff member. We found AHWs and HACC workers delivering informal services in many areas without adequate training or support. Where Indigenous staff are involved in palliative care service or as hospital ALOs, they are under-resourced and unsupported (see Chapter 6).

In residential care facilities with large numbers of Aboriginal or Torres Strait Islander staff, the atmosphere is noticeably different. In these places the presence of a high percentage of Aboriginal or

Torres Strait Islander workers, both in domestic as well as health professional roles, was important.

Good practice requires:

- employment of men and women of Aboriginal and/or Torres Strait Islander descent;
- that Aboriginal and/or Torres Strait Islander staff are not isolated (ie they should be located in or associated with Indigenous organisations or associated with other Indigenous workers);
- adequate support and supervision, and professional debriefing (especially around grief and loss); and
- appropriate training.

The need for a review of the employment conditions of hospital ALOs was raised with us more than once. Some organisations have flexible award conditions to enable ALOs to attend to cultural responsibilities in 'sorry' time.

Training needs have been outlined in Chapter 7, and examples of training initiatives are given in that chapter.

Royal Perth Hospital has recently made an innovative appointment of an Aboriginal nurse in a position described as Indigenous Clinical Advisory Nurse. Creation of this position recognises the need for a combination of medical and cultural advocacy in the hospital. The position works closely with the palliative care team in the hospital.

An interesting model for improving service delivery was discovered in the position of HACC development worker. In this model a development worker/ALO is appointed to an organisation in a town or region but works across a range of HACC services, providing advice about their service delivery from an Aboriginal or Torres Strait Islander perspective, undertaking hands on liaison and also providing regular cultural awareness training for mainstream services, including provision of information about Indigenous services.

8.4 Access and coordination issues

8.4.1 ALO involvement

We came across several examples where a hospital ALO had been actively involved in promoting the use of hospices and had arranged familiarisation visits to these facilities for community leaders and client families. These activities seemed to have been very successful in promoting the use of the facilities and expanding the choices of community members.

8.4.2 Care pathways

Hospitals with discharge facilitators who involve both palliative care services and the ALO or other cultural advocate are considered to be demonstrating good practice. There are very few of these. Those that also involve the family are even rarer.

The need for some sort of palliative care pathway into which cultural liaison or brokerage could be built was raised by several service providers. Two examples of pathway development in other (non-palliative) areas were discovered. The Hospital to Home Pathways (HOP) pilot project being run in Adelaide has the goal of:

Improving the continuity of care for HACC eligible patients of The Queen Elizabeth Hospital (TQEH), by developing, piloting and evaluating a collaborative and effective pre-admission and discharge planning process with Metropolitan Domiciliary Care – Western Region (MDC–WR), Royal District Nursing Service (RDNS), Adelaide Western Division of General Practice (AWDGP) and the Centre for Allied Health. [HOP Project Plan August 2002]

This project targets Indigenous clients and builds Indigenous HACC service providers into the loop. The Pathways Committee has a representative from an Aboriginal and Torres Strait Islander service provider.

The second example is the *Management of Diabetes Mellitus in Adults – Queensland Standard Care Pathway* (2000), where the primary care coordinator is the GP or the Indigenous health worker. The pathway documentation includes a wall poster / flowchart. Such a pathway flowchart or checklist, including 'built in' elements of cultural advocacy could be developed for palliative care.

Accessibility and responsiveness of palliative care specialists to requests from AMSs were highly valued where these occurred.

8.4.3 Coordination between settings of care

Chapter 5, Section 5.3 described the need for a 'tagging' system to prevent palliative clients receiving inappropriate treatment in emergency wards. Two examples of such systems were discovered. One involved a 'tag' or 'alert sheet' in the hospital file, similar to an allergy tag. The other involved a registration booklet given to the client on admission to the palliative care service which described key features of the care plan, contact details for palliative care team members, and could include the patient's directions regarding resuscitation.

8.4.4 Models of coordination

There needs to be better communication between the service providers about who is dealing with what, eg there should be agreements about communication protocols between the Aboriginal liaison staff of the hospital, the Aboriginal health unit and the domiciliary care and other service providers. In general, more communication is better. Talk to each other and check that the matter is being dealt with appropriately. [domiciliary care worker]

Models of coordination vary. In many places weekly team meetings between all key service providers are held. Aboriginal or Torres Strait Islander service providers are not usually involved, even when there are Indigenous clients.

In many places, coordination between hospital and home-based palliative care service providers is quite good and care is coordinated by case management meetings. Aboriginal or Torres Strait Islander health service providers and AHLOs are not usually involved, however.

In one New South Wales health service district the community nurse coordinates relationships between service providers. Care reviews and meetings take place on an 'as needs' basis. (Apparently this does not work perfectly because the coordination role of community nurses is sometimes forgotten by the hospital team). There is no regular contact with the ALO and no contact with Aboriginal health organisations except in NAIDOC week. The community health palliative care staff are aware which hospitals have ALOs but have no regular contact with them. Discharge planning had not included the ALO, but this is

changing, and the ALO is now invited to explain palliative care to Aboriginal clients and arrange familiarisation visits to the hospice. This coordination model could easily accommodate involvement of the local AMS on a regular basis, rather than the AMS having to contact the palliative care unit for help on occasion.

In a regional centre in the Northern Territory, the palliative care team and community care team meet with the Aboriginal health service on a monthly basis. The AMS says this team approach works well but could be improved, as it is not clear who is the team leader and it is confusing to clients because three service providers are involved. The AMS also said there is a lack of feedback from each of the organisations.

In another regional centre in the Northern Territory, monthly palliative care meetings also include representatives of Indigenous and non-Indigenous organisations.

The high turnover of staff in small regional towns often means that new staff members may not be aware of local processes. For example when we met with hospital staff in one Northern Territory town, they reported the AMS no longer attended discharge planning meetings and assumed they were no longer interested. When we met with the AMS and mentioned they no longer attended these meetings, the AMS doctor who was relatively new was not aware they had ever attended the meetings.

A major example of breaking down barriers and building relationships between Indigenous organisations is in [2pop3] region where the [2AB] Cultural Health Service, [2AF] Health Service and the community have recently formed a partnership to provide an integrated, culturally appropriate health care model for the communities of the [major river] Valley in order to avoid duplication of services and to foster continuity of care. [Western Australian regional area]

Relationships once developed need to be maintained, especially in areas which experience high staff turnover.

There were also good examples of services working collaboratively.

The mainstream HACC service and Indigenous HACC service often share clients. This sometimes happens when there is a staff shortage (often due to 'sorry business') in the Indigenous service. Recently the mainstream HACC service outsourced four CACPs to the Indigenous HACC service. [Northern Territory]

Identified need

An AMS in a metropolitan area would like to work out a way to support the AMS doctor and community nurse to provide palliative care support at home, should they have a client who refuses to be referred to mainstream palliative care services. They reported a case where a client (who would have nothing to do with mainstream services) was dying at home and, at the last minute, the doctor had to go in the middle of the night to access drugs and other needed items (which would normally have been available through the palliative care service). The AMS wanted to know whether a patient could be admitted to a palliative care program without seeing one of the palliative care team? This also raised the question of whether family members could get palliative care support if the patient had refused to see the mainstream palliative care specialists. This latter question was also raised in other places.

8.4.5 Opportunities for the funding coordination of service

Enhanced Primary Care (EPC)¹ multidisciplinary care planning involves team-based management of a patient's complex care needs. An EPC multidisciplinary team care plan is a written, comprehensive, longitudinal plan for the care of patients with one or more chronic conditions and complex care needs, developed and managed by a multidisciplinary team comprising the patient's GP and other health and care providers.

EPC items provide Medicare rebates for, among other things, '*care planning and case conferencing for people of any age who have chronic medical conditions and have complex care needs*'. Such case conferencing can lead to better quality of care and better collaboration between doctors and other care providers and is highly appropriate for palliative care clients.

EPC multidisciplinary care planning provides added incentives for GPs and AMS doctors to work with palliative care providers as a member of the care team, since a Medicare rebate is available to the doctor, provided that the client is enrolled in Medicare.

8.4.6 Missed opportunities for coordination and cooperation

Several practices or approaches need to be avoided in order to achieve well coordinated services that include appropriate Aboriginal and Torres Strait Islander participation.

Rivalry between service providers

We found some examples where 'possessiveness' over clients prevented the delivery of good service. This may take place between GP and palliative care service provider, between hospital and community based service provider, between an AMS and palliative care provider, between consulting oncologists,² or even between ALOs from 'rival' hospitals.

'Gate-keeping' by AMSs

Concern for loss over control of the client's interests is said to be one reason why 'gate-keeping' behaviour occurs, although some AMS doctors admitted that it was sometimes based upon an assumption about the wishes of clients (i.e. that the client would not want to use a mainstream service). It is unlikely that this occurs in other fields. Do AMS doctors not refer clients to other specialists, for example to cardiologists, because they are mainstream service providers and their clients may not want to go?

The example of the Queensland doctor (cited in Chapter 4, Section 4.4.1), who did not refer clients to palliative care services because he was under the impression that palliative care was 'life prolonging' and believed that Aboriginal people accepted death with equanimity, is extremely serious. It underscores the importance of training about palliative care for GPs and the need for more robust cultural awareness training so that practitioners will not make simplistic assumptions on behalf of their clients.

'Gate-keeping' behaviour also underscores the need for more trained Indigenous staff who can support clients to access services.

¹ See the EPC Website at www.health.gov.au/epc or contact the Medicare Enquiry line on 13 20 11.

² In one remote town it was reported that a city-based oncologist from a particular city hospital consults to the local base hospital. If clients have visited a different city hospital and their specialist is unwilling to pass them over to the consulting oncologist, they will miss out on being referred to the palliative care coordinator who gets most of her referrals from the visiting consultant.

State health boundaries

We found some examples where Aboriginal and Torres Strait Islander clients were not receiving the best palliative care services available because of Health District boundaries. Patients might attend a hospital in one district but live in another and palliative care services may not be coordinated across these boundaries.

8.4.7 An example (recommendation for) of an integrated service

Kirk, *et al* (2000), reporting on a study of breast cancer, recommended that Aboriginal women and Torres Strait Islander women should have equitable access to a range of culturally appropriate palliative care services. Key activities identified to implement this recommendation included:

- women's cancer screening services should work with existing cancer support and palliative care services to identify and develop strategies to improve services to better meet the needs of Aboriginal women and Torres Strait Islander women;
- cross cultural literature and audiovisual material about the later stages of breast cancer and loss and grief should be developed;
- opportunities for existing cancer support and palliative care services should be identified, to improve services to better meet the needs of Aboriginal women and Torres Strait Islander women;
- initiatives of government and non-government organisations need to be supported, for example, the Queensland Health Indigenous Workforce Management Strategy to increase the number of Aboriginal women and Torres Strait Islander women employed in cancer services, including screening, management and treatment, palliative care and support services in order to increase community trust and acceptability;
- the training of Indigenous Health Workers should be promoted and supported, especially in rural and remote areas, in counselling, domiciliary and palliative care; and
- the number of Indigenous health workers employed in palliative care and domiciliary care services should be increased.

8.4.8 Working together – making it happen

At the suggestion of an Aboriginal HACC worker from an AMS in a rural town in Victoria, all the palliative care services in the region came together to develop a set of local protocols or regional guidelines to take account of cultural issues. These draft guidelines are shown in Appendix 12. Newsletter No 3 outlined a process for developing such guidelines.

8.5 Standards for the delivery of palliative care

8.5.1 Whose standards?

Recently there has been considerable discussion about the development of standards for the delivery of palliative care (see for instance Jellie and Shaw (1999) and PCA *Standards for Palliative Care* (1999)). Development of standards for delivery of care to Aboriginal and Torres Strait Islander clients should be approached with extreme caution. Practice standards must be reviewed to check their applicability to all

Indigenous situations. In some cases the best palliative care for a person may involve their return to an environment which would not be regarded as meeting medical or personal care standards. Practice standards developed must give due weight to emotional, social, cultural and spiritual issues.

Willis (1999) states *'the issue is not simply to modify elements of palliative care so that cultural differences in belief and practice around death are accommodated, but to recognise that different cultures 'do death' in different ways, and that institutions for the provision of palliative care are bound up on the 'way of dying' of the culture in which they originated.'* (p 427). He goes on to discuss the concept of a 'good death' (as defined in terms of modern hospice practice), as opposed to what he terms an 'acceptable death' (p 434) as defined in terms of the desires and expectations of the patients and their families. The implication is that one person's 'good death' may be another person's 'bad death'. Willis also points out that changing minor details of service delivery such as food or the numbers of visitors, or the time allowed for visits (though they may be necessary) are inadequate responses to cultural differences in the underlying assumptions of care.

The setting of standards in relation to these matters is not simple.

Whilst it may not be practicable to set prescriptive standards for the delivery of culturally appropriate palliative care, it should be possible to set standards for appropriate cross cultural communication and practice. These should ensure, for example: effective input into policy and cross cultural practices by appropriate Indigenous organisations; employment or participation of Indigenous staff where possible and appropriate; effective communication between Indigenous and non-Indigenous service providers, and so on. Ultimately the effectiveness of such standards must be determined by consumers – palliative care clients and their families – so observance of these standards would need to be monitored or measured by (culturally knowledgeable) third party interview of consumers.

Objective 2.1 of the *National Palliative Care Strategy* (2000) suggests that resources should be tied to good practice. There is a danger in tying resource allocation to good practice because this may disadvantage those who are already disadvantaged. Where consumers are not well served by existing services, action needs to be taken (and resources applied) to ensure that those services are improved (or replaced) rather than withdrawn because they do not meet standards.

8.5.2 Monitoring service delivery

There is a need for effective quality control and improvement. Specifically, mainstream palliative care providers should develop systems to check on the quality of their service to Indigenous clients. Scheduled service reviews, for example conducted six months after a death and using an Indigenous reviewer would be a useful way for providers to discover how their services could be improved.

8.6 Some service delivery models

The models described in this section were selected because they are said to work well in the communities where they operate. It is probable that none could be directly 'transported' to another region, however they may contain elements that would be appropriate in other places.

8.6.1 Remote community with multipurpose funding (central Australia)

In this model, care is provided in the home by the family with support from clinic staff (doctors, nurses, health workers) with whom the family are familiar. Clinic staff are supported by a specialist palliative care nurse who can provide advice and equipment (mattresses, mosquito nets, etc). When the person is about to pass away the family arranges for them to be transferred to the clinic which has an overnight stay room for the patient.

After the person passes away, the deceased can remain at the clinic mortuary for 24 hours and then must be either buried or flown to Alice Springs (as the mortuary is not suitable for long term use). When funeral arrangements are made the deceased is flown back to the community at the expense of the family. If members of this community have to fly to Adelaide or Alice Springs for treatment, arrangements can be made for a *ngangkari* to visit them. In Alice Springs a community representative liaises with the hospital and patient. People are usually flown back to the community when they are close to death if this can be achieved (this may not always be possible due to limited flights).

Elements of this system that were thought to be best practice were:

- the clinic staff are known to the sick person they are visiting;
- the clinic staff are supported by a specialist palliative care nurse who has access to appropriate (though limited) equipment; and
- the palliative care nurse has access via her network to advice from another palliative care specialist.

The aspect of this system that did not always work well was that there were not always enough family members with the ability to make a sustainable commitment to look after the person. It was very hard on families. The fact that a palliative care nurse was employed in the community was a 'lucky accident' and had not been planned.

8.6.2 Aboriginal controlled medical service in rural-regional setting with registered nurse and HACC worker

As well as town-based clients, many Indigenous people from throughout the region (often travelling long distances) come to this rural town for health care.

HACC workers provide home care, cleaning and linen for clients who need palliative care at home, while the medical centre nurse looks after medical needs. The nurse is always accompanied by an Aboriginal worker. There is no special funding for this.

Weekend work is not funded. If the nurse or HACC staff give their phone number for contact over the weekend, they provide the additional service in their own time.

The Aboriginal housing and hostels unit arranges accommodation for clients from out of town but often there is no furniture for them. HACC workers will often try to help with this.

Although there is a hospital in this centre, some Indigenous people do not like to go there. A mainstream palliative care team operates out of the hospital. Many Aboriginal people prefer to attend the AMS rather than go to the mainstream service where they often have communication problems. People especially don't like going to the palliative care room where people have died.

Patients from out of town would usually prefer to go home but there is often no hospital or no culturally appropriate facility where they live and their families may not feel able to provide care. There is no funding for transport for people to go home.

We were told by an Aboriginal health worker that:

Some time ago, an old man from out of town died. The senior men from that town came in and wanted to blame the medical centre staff – it was very difficult but it was all right in the end. There hasn't been any more of that sort of trouble, but the accountability put on Aboriginal workers is a constant pressure.

Palliative care is added on to what you can do. There is no funding for it. We should be able to provide 100% care not 50% care. [AHW, South Australia]

8.6.3 City hospital with Aboriginal liaison officer (ALO)

The ALO in this hospital provides a number of services:

- assists with communication and explaining medical terms, helping with travel arrangements for family and extended family;
- arranges appropriate space in the hospital to accommodate family visitors;
- ensures there is a culturally sensitive environment for children and family that allows for their cultural practices (many patients come from remote and traditional communities);
- coordinates with the local community to find appropriate accommodation and support for families visiting from outside the metropolitan area;
- makes contacts to arrange for appropriate mortuary and funeral arrangements; and
- puts families in touch with a range of mainstream services if they want to access them.

8.6.4 Metropolitan Indigenous aged care facility with flexible funding

This facility has 'high care' and 'low care' beds and will be gaining some community aged care packages. It is flexibly funded and so can provide some palliative care for residents who are approaching death, although this stretches available resources.

The facility is not funded for the additional nursing care required when people need high level pain management or other palliative care. Housing and accommodation for family members, many of whom come from some distance, also stretches the resources of the facility. Although as much palliative care as possible is offered, people usually pass away in hospital where they are moved at the last minute.

This service identified certain dilemmas and needs. They do not want to use the label 'palliative care' because it is like making a decision that people will die. They need extra resources to help clients through this time at the end of life, but they want to build it in without labelling it. This is a cultural issue. There may also be a dilemma about the legitimacy of this use of funds and so a reluctance to raise it with funding bodies. A possible solution suggested by the service provider is to develop a relationship with an existing mainstream palliative care provider that could provide the extra medical support for their clients.

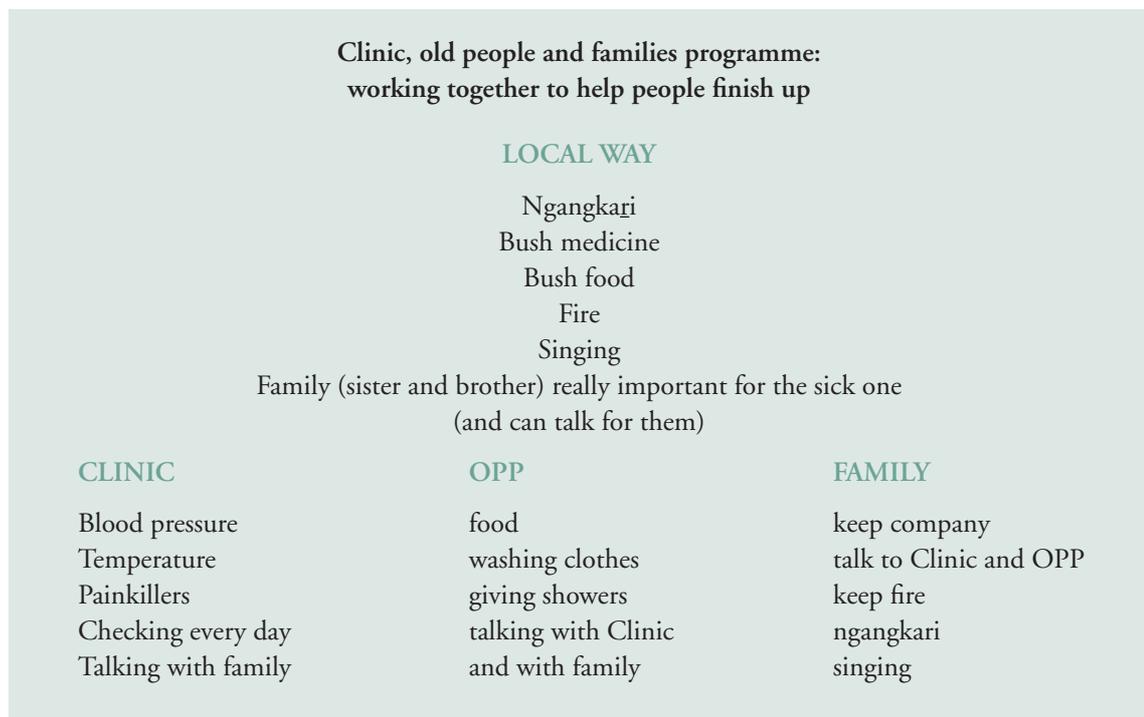
8.6.5 Metropolitan community-controlled health centre working with a mainstream service provider

This metropolitan health centre has been actively involved in the palliative care of several clients in recent years. They have played a key role in explaining palliative care options and available services to clients and their families. While the centre staff are as involved as they can be, and recognise the importance to the client of a familiar provider, they have been instrumental in facilitating the use of mainstream service providers. They have worked with the Royal District Nursing Service (RDNS), which has an Aboriginal liaison officer, to provide appropriate care and support. This was essential because the community controlled health centre is a 9.00 – 5.00 operation.

This organisation has identified the need for an Indigenous coordinator attached to their centre who can assist with communication and liaison between the centre, the client and the mainstream provider. As well as providing information about palliative care and what it can offer, the liaison officer would need to build trust and facilitate the development of a relationship between the family and the service.

8.6.6 A Northern Territory model

In the model depicted on the following page, the people in a large remote community describe how the clinic, the aged care program and the family work together to provide care according to local traditions. The diagram and notes presents the model as the community see it.



The following are the principles involved in palliative care as identified by this community:

Finishing up when people cannot get better

- Old people and sick people need to pass away in their own country with their own family
- It is really important people be brought home to finish up. Families need to gather, camping around and say goodbye
- Really important people stay at home and doctors and nurses don't send them last minute to hospital
- Airplanes are really frightening for old people
- We don't like seeing our old people going through cruel things like kidney machines
- It is not right for our people to have tubes and too much different medicine at this time
- People need help to settle down properly and be happy – it is important they have no pain, pain medicine is all right
- It is important in our way that we see the passing with our own eyes

8.6.7 The empowerment models – remote communities

Northern Territory

The Central Australian Territory Palliative Care service provides a model of empowerment. It offers education and support to health clinic staff in remote Indigenous communities who carry out most of the day-to-day care of clients and advises on symptom management. This model allows local staff to work out local solutions and relies on the health clinics and aged care workers to work closely together with the client, the traditional healer and the family.

Western Australia

Because of the vast distances, scattered population centres and the difficulties some communities have in accessing medical services, the palliative care network developed a decentralised model for the delivery of palliative care. Local medical practitioners and hospitals in larger centres are responsible for primary medical care and the community nurses and Aboriginal health workers are responsible in remote centres. Because of the wide cultural diversity of Aboriginal groups throughout the region they have developed a flexible model to accommodate local cultural and social needs.

8.6.8 Two case studies from central Australia

The Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council (NPYWC) provided the following case studies. They illustrate how communities deliver palliative care services without palliative care funding.

Mutitjulu Disability House 29.04.01 – 03.06.01

A frail aged man at Mutitjulu who was wheelchair-bound was in Alice Springs Hospital and returned to his home at Mutitjulu. The family had a meeting with the clinic at Mutitjulu and he decided that that if he got sick again, he didn't want any invasive treatment but antibiotics were OK, and that he didn't want to be taken back into Alice Springs. If he was to get very sick and pass away he wanted to be in the community where all his family were.

His carer was finding it difficult to look after him as his health was failing and winter was approaching. His house had no heating and he was sleeping in a room with many other people. They decided he should go to Hetti Perkins in Alice Springs for respite. There were no beds available and he did not want to go to Alice Springs. He wanted to stay close to family members in his home community, Mutitjulu.

His carer suggested he stay at the Mutitjulu Disability Respite House (MDRH) where he could have a room to himself and paid carers but still be in his home community. His granddaughter and her husband came along to the house and acted as primary respite carers.

The MDRH is primarily a respite facility for people with disabilities but can cater to frail aged people when needed. Under normal circumstances respite is restricted to two weeks. He stayed at the house for five weeks.

One morning he had a talk with his family and told them how he was happy and knew that his family would be OK. He also had conversations with his family with regards to his possessions. He requested that the MDRH not be closed for an extended period and for the family to continue to live in his house and that only his personal possessions are destroyed.

He passed away a few hours later.

The house was closed for one week out of respect.

Funding for this respite opportunity came from NPYWC Cross Border Carer Respite Centre.

Palliative care case study AP lands

In December and January of 2000/1 the NPYWC Aged Care Support Project for AP lands (the project) was able to facilitate the provision of palliative care for a frail aged client on the AP lands.

With an elderly and sick husband and no other appropriate family to care for her, Nganampa Health clinic staff had sent our client to Alice Springs Hospital (ASH) for observation. The project liaised closely with our client and her husband, with ASH and Nganampa Health staff, and ascertained that her condition had progressed to a palliative care situation. Her wish, and that of her husband, was that she return to her community and be attended there by clinic staff. Unfortunately, the inappropriateness of her usual accommodations, a swag on the ground under a makeshift wiltja, and the staff shortage at the community clinic over the Christmas period, meant that the clinic was unable to ensure an appropriate quality of care on her return to the community and therefore recommended against it.

The NPYWC project staff worked quickly to negotiate a solution to this situation. We were able to employ a qualified and appropriate care attendant through a nursing employment

agency, who was willing to travel with our client and project staff from Alice Springs back to the Lands. We were able to locate temporary accommodation in a neighbouring community where our client's husband had family and which was therefore an appropriate place for them to stay. The care attendant resided with our client and her husband, and in liaison with the community clinic staff, monitored and administered patient medications, provided daily personal care, including meals, and ensured the last weeks of our client's life were comfortable. The importance of the palliative care that NPY was able to facilitate for this client cannot be under-estimated. She was provided with the medical attention and personal care that she needed whilst being able to be with family, speak her language and see her country. She passed away quietly on January 3, 2001 aged 79.

Funding for this respite opportunity came from a combination of two NPYWC HACC programs (South Australian Office for Ageing, Department Human Services): the Aged Care Support Project on the AP lands and Carer Respite Program.

8.7 Findings and implications

8.7.1 Good practice highlights

Key elements in good delivery of care include: early referral; cultural advocacy and brokerage; good communication and relationship development; clear coordination (i.e. everyone's role is clear); regular case management meetings, including cultural advocates; continuity of care; and flexibility and responsiveness which recognises individual needs.

In the course of our investigation we discovered aspects of practice which we considered to be innovative or 'good'. Some highlights are listed below:

- Employment of Aboriginal and Torres Strait Islander staff;
- Palliative care services in which the providers view themselves as coaches for the family, providing training and support so that they can look after a family member at home (see Section 8.2.1);
- The provision of a comfortable and 'neutral' place where people can pass away that is readily accessible to family members, and will not result in cultural avoidance problems after the death;
- Good design and management of in-patient and residential palliative care facilities to accommodate cultural practices (see Sections 5.4.3 and 5.4.4 and Appendix 8 and Appendix 9);
- Pathways of care (see Section 8.4.2) which include checkpoints for cultural advocacy and cultural safety;
- Workshops and planning sessions in which mainstream and Indigenous service providers develop regional network guidelines to assist them to communicate with each other and deliver more integrated services (see Appendix 12); and
- Provision of valuable practical assistance to families by assisting in the funeral arrangements and the preparation of the 'order of service' and eulogies at the funeral service. Other innovations and good practice in bereavement care are provided in Section 5.5.

8.7.2 Standards and monitoring

In some cases the best palliative care for a person may involve their return to an environment which would not be regarded as meeting usual medical or personal care standards.

It may not be practicable to set prescriptive standards for the delivery of culturally appropriate palliative care, however it should be possible to set standards for appropriate cross cultural communication and practice, such as ensuring effective Indigenous input into policy, ensuring employment or participation of Aboriginal and/or Torres Strait Islander staff where possible, and ensuring effective communication between Indigenous and non-Indigenous service providers.

Practice standards must be reviewed to check their applicability to *all* Indigenous situations. Practice standards must give due weight to emotional, social, cultural and spiritual issues. From an Indigenous perspective, an initial starting point for any standard may be that a local Indigenous cultural broker or patient advocate, acceptable to both patient and family, is included in palliative care planning for Indigenous patients.

Observance of these standards would need to be monitored by culturally knowledgeable third party interviews of consumers (see Section 8.5).

There is a need for effective quality control and improvement. Specifically mainstream palliative care providers should develop systems to check on the quality of their service to Indigenous clients. A program of service review conducted 6 months after a death and using an Indigenous reviewer would be a useful way for services to discover how their services could be improved (see Chapter 8, Section 8.5.2).

If services are not up to standard then action needs to be taken to ensure that those service are improved rather than withdrawn because they do not meet standards.

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Chapter 9

Resources, fees and funding



9.1 Funding

9.1.1 Australian Government funding for Indigenous palliative care

The *National Palliative Care Strategy* was endorsed by the Australian Health Minister's Advisory Council (AHMAC) in October 2000.

The Australian Government made a total of \$162 million available for palliative care throughout the five years of the current Australian Health Care Agreement (1998-2003). Of this, \$151 million has been broadly allocated on a per capita basis to States and Territories for continued service provision, and \$11 million for the Australian Government to implement a national program of initiatives.¹

In May 2002, the Australian Government committed a further \$55 million over four years for Australian Government activities to support improvements in the standard of palliative care offered in local communities.

This total of \$66 million funding for national activities, known as the National Palliative Care Program, is intended to improve the quality of palliative care through the provision and coordination of a national program of initiatives. The national program is being implemented across the following six broad priority areas:

1. Provision of an expanded range of medications for palliative care in the community;
2. Assistance for families and increased support to other care networks;
3. Education, training and support for the primary care workforce;
4. Increasing the range and reach of palliative care services;
5. Capacity building in the palliative care research community; and
6. Performance information development.

Indigenous palliative care projects funded by the Australian Government

Some of these funding initiatives will have outcomes which flow indirectly to Indigenous service users. Two major initiatives of the *National Palliative Care Program* were directed toward Indigenous Palliative Care: this study of the palliative care needs of Indigenous peoples; and the *Guidelines and education and training resources in Indigenous Palliative Care Project* which is jointly coordinated by Wodonga TAFE and the Mungabareena Corporation. The Guidelines project has three major components:

- to develop national guidelines for staff at all levels who provide care to terminally ill Aboriginal and Torres Strait Islander peoples in mainstream palliative care services or hospices;

¹ Funding information drawn from Australian Government Department of Health and Ageing, *Overview of Commonwealth Funded National Palliative Care Initiatives as at November 2002*.

- to develop a national education and training resource about caring for terminally ill Aboriginal and Torres Strait Islander peoples, for staff at all levels in mainstream palliative care services or hospices; and
- to recommend ways that the guidelines and the education and training resource can be implemented.

The Guidelines project will make use of the information gathered by this study.

In the Northern Territory, the National Health and Medical Research Council (NHMRC) has funded a multi-disciplinary research project called *Innovative Models of Palliative Care Health Service Delivery to Rural Areas* which is exploring service delivery to Indigenous people living in rural areas of the Northern Territory. The expected outcome is the description of an innovative model for rural and remote palliative care service provision to Indigenous people based on an understanding of what is presently available, which models work most effectively and what is needed. The project is being directed by the University of Queensland.

In 2000, Ngaanyatjarra Health Council secured funding through the Commonwealth Office of Rural Health (Regional Health Services) for a two-year palliative care project, including the development of a manual for health professionals. The project was based in the remote Wannarn community in the far eastern region of Western Australia where the Ngaanyatjarra Health Council employed a palliative care nurse with extensive experience working with Indigenous clients. The position has been developed to include general support/education and clinical work. This made it easier for nurses to go into homes and not to be seen as just the 'dying nurse'. The project was expected to conclude in June 2002 and no further funding was expected through this program.

9.1.2 State funding for Indigenous palliative care

State informants told us that most of their palliative care funding comes from State funds (for example, in Victoria \$44.5m is funded by the State government² and \$7m comes from the Australian Government through the Australian Health Care Agreement (AHCA). Other Australian Government funds flow from the Medicare schedule.

None of the States has made any specific allocation for Indigenous palliative care with some exceptions related to specific projects:

- The Western Australian Health Department has allocated a one off payment of \$100,000 to Aboriginal and Torres Strait Islander initiatives in palliative care. They have also allocated approximately \$40,000 to Gascoyne Health to develop 'creative' palliative care initiatives for a number of AIDS clients (including Indigenous), in the Gascoyne area;
- In Victoria, \$30,000 has apparently been provided by the Department of Human Services to the Centre for Education in Grief and Loss which is working with VACCHO on a project investigating Indigenous grief and loss;
- In New South Wales, funding has been allocated to a project in the New England region to study the needs of the Aboriginal community in relation to palliative care (this project is just getting underway); and
- In Broken Hill, the New South Wales Government has funded (with some additional Australian Government funds) a project which aims to increase access to and awareness of mainstream palliative care services and is investigating ways of integrating mainstream and Indigenous services. The project is developing protocols for cultural and clinical services to allow community-controlled and mainstream services to work together. An advertising campaign using local media is planned.

² Note that the \$44.5m quoted above includes funding of two Chairs of Palliative Medicine.

In South Australia a research project funded by the non-government sector is underway: The Royal Flying Doctor Service and the South Adelaide Palliative Care Service have supported a project to examine access to palliative care for people in remote areas of South Australia. Negotiations have commenced with the remote Indigenous community which will be the focus of the project. The project is also supported by Apex.

Apart from these projects, no funding is set aside for Indigenous-specific palliative care initiatives.

In New South Wales each health region has developed (or is in the process of developing) a palliative care strategic plan. Those we have viewed identify Indigenous people as a special target group. These plans are general documents and do not have specific or costed Indigenous initiatives. Only one of the three documents (of 16) which we viewed had had active involvement of Aboriginal Health regional directorates.

Overall, State funding for specific Aboriginal and Torres Strait Islander palliative care has been limited and piecemeal. The approach of developing regional plans for palliative care is to be commended, however the components of the plans for Aboriginal and Torres Strait Islander clients need to be based upon identified local needs if they are to be effective.

Local and regional officials from:

- mainstream palliative care service providers;
- State run, Aboriginal and Torres Strait Islander local health units (including community health);
- the ACCHS; and
- Indigenous HACC or CAAP or home care programs

need to come together to identify priority actions and initiatives. These initiatives need to be funded and the outcomes monitored.

9.1.3 Structure of funding

Structure of mainstream services funding

Palliative care services are funded by State governments and through the Australian Health Care Agreements. These funds cover palliative care beds in acute care facilities as well as community based services. The private sector also provides services (hospices, nursing homes, community nurses, bereavement services) which are sometimes either partly funded by government or are brokered in by government.

Structure of Indigenous services funding

OATSIH funding

Indigenous health services are provided either directly by governments or are delivered by the community controlled health services (ACCHSs or AMSs) (120) which are funded by OATSIH. Most of these services provide only limited and informal palliative care services, with no trained and dedicated staff and no identified funding source.

AMSs receive grant funding on a global budget basis and can also access funds via Medicare or pharmaceutical funds either through the Pharmaceutical Benefit Scheme or under Section 100 of the

National Health Act (if they are remote). These organisations may also receive some State grants and access other Australian Government funds through special programs.

Primary Health Care Access Program Funding

A major new funding initiative in Aboriginal health is the Primary Health Care Access Program. This program was announced in the 1999-2000 budget and is now being rolled out. It has three objectives:

- to increase the availability of appropriate primary health care services where they are currently inadequate;
- to reform the local health system to better meet the needs of Indigenous people; and
- to empower individuals and communities to take greater responsibility for their own health.

PHCAP will establish a framework for the expansion of comprehensive primary health care services, including clinical care, illness prevention and early intervention activities and management and support systems, in a planned and coordinated manner in line with regional planning. [www.health.gov.au/OATSIH/pubs/phcap/]

The scheme is dependent upon completion of regional planning processes. Essentially it provides top-up funding (pooled and untied) to fill gaps in service delivery.³ Advice from the Health Financing Section is that all the regional plans are now complete; that none of them identify palliative care as an issue⁴ and that palliative care has not been identified as a priority in any of them. This would appear to be a serious missed opportunity with far-ranging implications for the future of palliative care in Indigenous communities.⁵

The reason(s) why palliative care has not been identified as a priority is not clear. It may be that palliative care is not a high priority, however it is also likely that the definition of primary health care used during regional planning did not recognise palliative care as part of primary health care, as palliative care is neither curative nor rehabilitative (see further below) and/or that those at the planning table are uninformed about palliative care.

Discussions with some Indigenous health professionals who were involved in the development of the regional plans upon which the PHCAP funding is based believe that lack of consciousness of palliative care and lack of awareness of what it is and what it might offer was the main reason that it does not appear as a need, rather than that there are no needs for palliative care services. That is not to say that if there were greater awareness, it would necessarily be the top priority in Indigenous health. Indeed several AMS doctors we spoke with said that they would not regard delivery of palliative care services as a high priority. Doctors' views of course do not necessarily reflect the view of Aboriginal and Torres Strait Islander people.

The fact that palliative care is missing from the regional plans is partly due to the diversity of programs that PHCAP funds, and partly due to a lack of priority and profile for palliative care.

³ The PHCA funds available for Aboriginal and Torres Strait Islander health in a region are worked out by subtracting the amount already spent on primary health care and subtracting that from the PHCA funding base.

⁴ Personal Communication, Barney Lee, OATSIH (02) 6289 5292.

⁵ Planning at the sub-state level (eg strategic palliative care across five zones in the Northern Territory) is presently underway and this gap may be identified at that level.

Other sources of funding for palliative care

The following sources of funds for palliative care for Indigenous clients were identified by informants. Not all of these are legitimately accessed for palliative care.

- Multipurpose funding;
- Indigenous Flexible funding;
- Residential Care funding;
- Community Aged Care Packages (CACPs); and
- Home and Community Care (HACC) funding.

The multipurpose funding model appears to provide excellent opportunities for remote communities to gain access to funding for integrated palliative care services (see below). These funding schemes are described in Appendix 13.

Opportunities for additional funding of ACCHS in palliative care delivery

The Enhanced Primary Care items (see Chapter 8 Section 8.4.5) provide Medicare rebates for, among other things, ‘*Care Planning and Case Conferencing for people of any age who have chronic medical conditions and have complex care needs*’. As noted above, case conferencing is intended to achieve better quality of care and better collaboration between doctors and other care providers, and is highly appropriate for palliative care clients.

9.2 Structural funding issues

9.2.1 No specific funding

Virtually no funding has been made available specifically for Indigenous palliative care service delivery, capacity building or access programs. State–Australian Government framework agreements on Indigenous health do not pick up palliative care.

We are so busy just keeping our heads above water. The Framework Agreement with the Australian Government, State and [Indigenous health organisation] is not seeing changes happen on the ground. Funding needs to happen – we are asked to jump through hoops with all the data and information we are expected to provide. Shortage of staff means that there is no time to complete required paperwork. Palliative Care doesn't rate a mention in the Agreement. [hospital administrator of 25 years in remote area, Queensland].

State health departments advise that palliative care is not identified in Australian Government / State Indigenous Health Framework agreements, although these are very general documents that do identify the need for better access to and coordination of mainstream services as an issue for action.

9.2.2 Funding formulas – ‘cancer as proxy’

Funding for palliative care is based on numbers of cancer patients. 80-90% of palliative care clients are currently cancer patients. Renal, respiratory and cardio cases may be under-represented in palliative care numbers because traditionally these clients have not been referred to palliative care services. Because the

State funding formula is based on a cancer proxy it may not pick up the needs of high concentrations of HIV/AIDS, renal, cardio, and respiratory condition palliative care clients. Aboriginal and Torres Strait Islander people are highly represented in these client groups.

While the incidence of cancer amongst Aboriginal and Torres Strait Islander people may be similar to the mainstream population (lower for men in some areas), the death rate from diabetes is eight times as high and the death rate from respiratory and circulatory illness is three times as high (see Chapter 3, Section 3.2.3). Renal, respiratory and cardio cases need to be recognised as conditions likely to require palliative care (see Chapter 4 Section 4.5) and palliative care funding formulas need to recognise the prevalence of these conditions in Aboriginal and Torres Strait Islander populations.

9.2.3 HACC funding not available

HACC funding is no longer available for palliative care except where there were specific programs running in the past, and these have been set as a 'no-growth area'. This is explained in more detail in Appendix 13. Despite this, in many areas Indigenous HACC programs are delivering quasi palliative care services because either there is no suitable alternative available or none which people know about or are willing to access.

This is a critical issue for Indigenous palliative care. There are effective and vigorous networks of Indigenous HACC workers in all states and these HACC workers are a vital link between the community and the health system. The importance of 'a black face' in a palliative care team was stressed again and again. Currently HACC workers are undertaking palliative care work without funding or training. Their potential role as referrer and/or coordinator is very substantial, but is not being developed or supported.

9.2.4 Palliative care and Primary Health Care – the gap

Palliative care does not fit easily into the Primary Health Care definition, despite the fact that it is increasingly delivered in a primary rather than in a tertiary setting.

The World Health Organisation Alma Ata Declaration for Primary Health Care (1978), while extolling community participation and involvement, does not include palliative care in the range of services to which it applies. The Australian primary health care system accordingly includes a '*comprehensive range of preventative, promotive, curative and rehabilitative services*'⁶, however palliative care does not fit comfortably into this range of services.

Better Health Care, the major document written to explain and promote the primary health care model for Indigenous Australians⁷, does not mention the term palliative care anywhere and uses the word 'palliation' only once in an introductory section. There are no examples of palliative care in the documents, except for an example of how end-stage renal disease is being managed although this is not portrayed as palliative care.

The primary health care focus of Aboriginal and Torres Strait Islander health funding, and the poor fit of palliative care into the '*preventative, promotive, curative and rehabilitative*' modes of service delivery may be in part responsible for lack of funding for Indigenous palliative care programs. The importance of

⁶ (2001). *Better Health Care - Studies in the successful delivery of primary health care services for Aboriginal and Torres Strait Islander Australians*, Department of Health and Aged Care: 1-104.

⁷ *Ibid.*

palliative care being recognised as part of the primary health care system has been identified by Prior (1997). Funding for palliative care may be one funding gap which PHCAP will be unable to fill within current definitions.

9.2.5 Aged care and nursing home funding issues

There may be several issues in funding structures for aged care and nursing homes which stand in the way of effective delivery of palliative care. These include:

- adequate funding for end of life care in aged care facilities and in nursing homes. Service providers report that cost peaks for additional nursing at this time are not adequately covered by funding even if high care beds are available;
- aged care facilities with no high care funding cannot offer 24 hour care without family assistance;
- appropriate medication may not be available in these institutions if there are not two registered nurses present, although the same drugs could be administered in a private home with no nurses present;
- flexible funding schemes are available under the Indigenous Aged Care Strategy, although these do not seem to be used as effectively as they could be for palliative care provision. Flexible funding appears to be available for nursing homes as well as aged care hostels, some of which also have community-based packages. It is unclear whether it is legitimate to use aged care money for palliative care in these settings (see Appendix 13). Some Indigenous service providers may be reluctant to describe the service they provide as 'palliative care' for cultural reasons and therefore may not be accessing the funding they could, or it may mean that funding is not used strictly in accordance with the rules; and
- There is a need for funding to allow aged care facilities and nursing homes to broker in palliative care services for symptom management advice, cultural advice and support, and additional nursing care under some circumstances.

9.2.6 Multipurpose funding scheme not used by remote communities

Multipurpose service (MPS) funding (designed for rural and remote communities of less than 5,000 people) provides opportunities for the provision of funding for palliative care. It is used in only one Aboriginal community in Australia and there would seem to be scope for this type of funding to be used more widely. This funding provides a flexibility which facilitates appropriate palliative care service delivery.

The future of many mainstream community palliative care services (which either provide services to, or have the potential to provide services to, Indigenous clients) seems to be in doubt as Australian Government funding under current Australian Health Care Agreements (1998-2003) comes to an end. The Australian Government is in the process of negotiating new agreements with the States and Territories and an announcement is reported to be due in the near future.

9.2.7 No mechanism for palliative care services to buy in cultural advocacy services

This study has identified a need for mainstream palliative care services to have the capacity to purchase the services of appropriate Indigenous service providers, Aboriginal Health Workers and liaison staff, and cultural advocates and language interpreters.

Cultural advocates should be recognised as one of a suite of ancillary services which may be required. Funding needs to be provided to buy in these services as needed if they cannot be justified on a permanent basis. Service providers identified a need for a brokerage mechanism (and supporting funds), similar to the arrangements available for community aged care packages.

9.2.8 Gaps in funding due to lack of local coordination and poor regional planning

In one large town in Western Australia, we found major gaps in funding. As a result there were no home-based palliative care services except for an untrained volunteer service and a coordination position for cancer clients. In this town funding is provided to the hospital to provide a three bed in-patient service and a clinical management support role into the community, however there is no funding to provide the community with a 'hands on' nursing service. Silver Chain is no longer funded to provide palliative care nursing or personal care. As a result of staff shortages at the hospital, there is no 24 hour nursing service for palliative care clients and even the clinical management consulting role is not currently filled. There is no integration of services (bereavement, counselling, information). The only coordination role is jointly funded by Community Health and the Cancer Foundation of Western Australia and so can work only with cancer clients, not other palliative care clients. These services do not reach Aboriginal clients unless they have come through the oncology ward of the local hospital. Many Aboriginal patients diagnosed in Perth return to the community without appropriate referral.

This example points to the need for local service providers (including ACCHSs) to have a collective say in developing funding priorities in their communities. Without coordination, piecemeal applications for funds by individual service providers tends to result in major funding gaps.

9.3 Resource issues raised by participants

A number of resource issues were raised in the course of our exploration of needs and unmet needs. Not all of these are specific to the care of Aboriginal and Torres Strait Islander peoples; some are relevant to service provision generally.

9.3.1 Aboriginal and Torres Strait Islander staff

The need for Aboriginal and Torres Strait Islander staff is discussed in several sections of this report (see Chapters 4 and 5). There are only two services in Australia which employ an Indigenous staff member as part of the palliative care team. The experience of one of these was that the number of Aboriginal and Torres Strait Islander clients immediately rose once there was an Indigenous worker:

...relationships with remote communities have improved and there is an increase in Aboriginal clients. This has meant that the health worker is over-worked and we estimate that they need an additional 3 Aboriginal workers. [Palliative Care Manager]

9.3.2 AMSs not funded for palliative care

Aboriginal medical services do not have funds for palliative care. Any resources they use come from other sources. 'Resources come out of OATSIH clinic money, which places increased financial and staffing demands on the program.' AMSs have no funds to pay Aboriginal health workers for out of hours work.

9.3.3 Home care and home support and shortage of respite services

Many mainstream service providers complained that there were not enough home care hours for palliative care clients. Many home care providers were said to 'close their books' (i.e. decline to accept more clients) if they were approaching funding limits. This was reported in New South Wales, Queensland and in the Northern Territory (where this was especially mentioned in relation to town camps).

Aboriginal home care is only available for patients who meet the HACC criteria. Aboriginal and Torres Strait Islander clients often don't fit the HACC criteria because funds cannot be used to help relatives who might be caring for someone.

Many people, especially in remote areas, spoke about the lack of support which often meant that they had had to take a family member to hospital and/or had difficulty in accessing equipment.

Shortage of respite beds was identified as a major problem, especially in remote areas. There appears to be a shortage of respite services everywhere.

9.3.4 Difficulty accessing allied health services

Unacceptable allied health waiting lists

Ancillary services (eg speech pathologists, domestic violence counsellors, financial planners, hearing services, physiotherapists, occupational therapists) are inadequate, especially in country areas. Palliative care clients are sometimes placed on waiting lists for up to three months. This was considered unacceptable for someone who has only months to live. This issue is doubly important for Aboriginal and Torres Strait Islander clients who may have been referred late. In remote areas, these services are only located in major regional centres and without transport, access to them is impossible.

In Victoria, the length of time it took to access allied services was reported as a common problem, especially in country areas. For instance, there was a three months' waiting period for a speech pathologist.

HACC criteria and ancillary services

Young people apparently have difficulty accessing ancillary services because funding is not available for them from aged care sources. If clients cannot meet the HACC criteria then the services have to be paid for by the client or by the palliative care service provider. The funds available to palliative care services for these services (for example, in Victoria, unassigned funds of \$2,000 per month) are totally inadequate to cover most clients' needs.

Home modifications

In New South Wales we heard of a case where it had taken a month for the occupational therapist to visit the house to authorise modifications and by the time the work was done (three months later) the patient used the installed ramp only once, on his final trip to hospital.

Equipment

The equipment available is limited and there are no resources for delivery of equipment. In very few places was there enough equipment to meet the need.

9.3.5 Not enough funds for palliative care services

Palliative care services reported that there were often insufficient funds for:

- adequate bereavement and counselling support; and
- community awareness, especially multicultural (including Aboriginal and Torres Strait Islander) outreach;

'The service has been chronically under-funded since its inception.' [director of a palliative care unit, South Australia]

CNC hours

In one place in New South Wales the recent reduction of CNC hours is likely to impact on capacity to deliver services in rural areas.

Lack of weekend hours for CNCs and palliative care nurses

There were several stories of clients who had a weekend crisis because there was no access to trained palliative care staff at that time. Patients or their carers had had to call a GP who did not know about medication, or called an ambulance and sent the patient to a hospital emergency unit.

Home visiting nurses

In two adjoining health districts in New South Wales the shortage of resources for home visiting was evident in different ways. One district provided after hours and weekend visits and had a three week waiting list for people to be visited for assessment; the adjoining district had no waiting list but provided no after hours visiting, though it did have a phone line.

In the Northern Territory a (non-Indigenous) palliative care nurse, based in a hospital and employed part-time Monday to Friday, described her situation as very stressful because there are no other services to provide nursing care on weekends or whenever she was sick or on leave. Instead clients would have to go to hospital for care or HACC workers would check on the client when delivering meals and medications.

Eligibility issues and funding levels

Some services said that they would be able to provide services to a larger range of clients (eg motor neurone disease and cystic fibrosis) if they had more resources.

In Queensland, it is apparently difficult to access palliative care funding without a medical prognosis of under 3-6 months. Patients often have to be discharged and re-admitted.

A palliative care service based in a major base hospital in Queensland has run over budget for the past three years and has had to cease providing services for the last three months of each financial year.

The integration of palliative care services into end stage renal management (see Chapter 4 Section 4.5) will require funding adjustments.

9.3.6 High turnover of staff in regional areas

This is a major issue for Indigenous clients, as replacement staff are not culturally aware and do not have a relationship with the Aboriginal and Torres Strait Islander community.

9.3.7 Remote area staff are overworked

Several Indigenous and non-Indigenous workers providing services to remote communities spoke of feeling overworked, under-resourced and unsupported. An Indigenous worker who had spent three months working in a remote community clinic said she had received no support from the regional office during that time and believed that regional office management staff had no understanding of the difficulties and working conditions of remote area workers. She said that even a phone call once a month would have helped.

A non-Indigenous remote area worker spoke of the unrealistic expectations of senior management in regional areas, particularly about workplace health and safety issues in areas where all the clients are Indigenous and many are living in bough shelters. She suggested that policy makers and management needed to appreciate that the situation for people working out bush was different and difficult. Remote area staff need to be supported and to feel that they are supported.

9.3.8 Need for more high care beds in Indigenous specific aged care or nursing homes

In several places where Indigenous aged care facilities exist, there is frustration at the lack of high care beds and the inability of facilities to offer adequate palliative care (see also Chapter 5).

9.4 Fees

In most areas there is no fee for palliative care services, however there is a wide belief amongst Aboriginal and Torres Strait Islander people that they will be charged a fee. This belief may discourage many Indigenous people from seeking out these services. One reason for this perception appears to be that there fees are usually charged for home nursing services (eg Silver Chain in Western Australia) even where there are none for the palliative care arm of the service.

In some States there is a fee for palliative care home nursing and home care but there are waiver systems if people can't afford to pay. Waiver systems may raise problems for Aboriginal and Torres Strait Islander clients who may be embarrassed (feel 'shame') by having to ask for a fee waiver, and/or may not have the social and communication skills to seek a waiver.

Many home care services now ask for a contribution from clients that is likely to be beyond the capacity of most Aboriginal and Torres Strait Islander households (see Chapter 3 – *Capacity* and Chapter 5 – *Medication*).

While most palliative care services are free, they have limited budgets to buy in allied health services and equipment. If the palliative care service has reached the end of its budget or equipment stocks, the only way clients can access some services is to pay for them themselves.

Hospital based palliative care is free to public patients and is reimbursed by private health funds.

Some (very few) health funds offer limited cover for home based services and while the number of funds doing this should be increased, this is largely irrelevant to Aboriginal and Torres Strait Islander clients who are unlikely to have private medical insurance. Where fees are charged by home nursing services it would be beneficial to Aboriginal and Torres Strait Islander clients if these could be reimbursed through Medicare.

9.5 Findings and implications

9.5.1 Structural funding issues

New initiatives in Indigenous funding focus on filling gaps in the delivery of primary health care. Palliative care does not fit the definition of primary health care (being neither curative nor rehabilitative) even though it is often (and increasingly) delivered by primary health care providers.

HACC funding guidelines now identify palliative care as a 'no growth' area.

The use of cancer as a proxy by most funding formulae for palliative care means that the needs of Aboriginal and Torres Strait Islander people who are highly represented amongst HIV/AIDS, renal disease, and cardio-vascular and respiratory disease palliative care clients may be overlooked.

Funding for Indigenous specific initiatives appears to have been piecemeal to date.

The multipurpose funding model appears to be an effective way of ensuring a flow of funds to meet identified local palliative care needs.

Funding packages similar to CACP packages may allow service providers to purchase cultural advocacy services when required for Indigenous clients.

Enhanced Primary Care Items should be marketed to palliative care and Indigenous health providers as a strategy to encourage the participation of Indigenous health providers into a more integrated (and better coordinated) service delivery for Indigenous clients.

In some circumstances, the funding arrangements for aged care facilities and nursing homes appeared to present barriers to clients receiving the best palliative care service in these facilities. Funding arrangements are needed that will allow aged care facilities and nursing homes to broker in palliative care services for symptom management advice, cultural support and additional nursing care when needed (see Section 9.2.5).

9.5.2 Some resource issues

Some key resource issues were repeatedly raised including:

- need for funding for Aboriginal and Torres Strait Islander staff;
- in general ACCHSs are not funded for palliative care, have no specialist staff and only operate 9.00 - 5.00, five days a week;
- there is a serious and widespread shortage of respite services, especially in places where Aboriginal and Torres Strait Islander people live;

- there are inadequate funds for personal care and home help services, which are not funded to provide palliative care and sometimes have to ‘close their books’ to palliative care clients;
- there are equipment shortages and inadequate funds to access equipment;
- funding restrictions have prevented some services admitting clients such as end stage renal clients;
- lack of funding for Indigenous liaison positions;
- insufficient funding for out of hours visits by palliative care specialists; and
- in some areas (eg Perth) there are no Indigenous-specific aged care nursing home facilities and/or where they exist, too few or no high care beds are available.

There are culturally determined needs which should be recognised as legitimate palliative care costs. These may include the cost of:

- temporary housing for the duration of the palliation (for cultural and/or socio-economic reasons);
- transport to take the client home (with adequate care);
- locating and accessing traditional healers;
- return of deceased to their home country or community;
- support to families and assistance with funeral arrangements as an essential part of bereavement; and
- support for cultural advocacy and language translation services.

9.5.3 Flexible funding

Funding needs to be flexible so that palliative care packages can be purchased where needed, for example, additional resources to allow people to be cared for in a remote community or in an aged care facility, or so that Indigenous staff with palliative care training or relevant cultural knowledge can be bought in (see Section 9.2.7).

9.5.4 Fees

In most States fees are not charged for palliative care services, however there is a widespread belief amongst Aboriginal and Torres Strait Islander people that these services do attract fees. Hidden costs of caring for family members at home, medication, home modification, equipment and power for heating and equipment, were all costs that most could ill afford to pay.

The absence of fees (and fee waiver schemes) needs to be better publicised, and funding support schemes should be developed to assist people in hardship who cannot afford the ‘hidden costs’ of caring for someone at home.

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Chapter 10

Findings and conclusions



10.1 Key findings

Generally, the Aboriginal and Torres Strait Islander people we interviewed said that they thought palliative care was a good idea. Palliative care could give them the support they needed to look after family members in their own way and could provide the knowledge and advice they needed and allow them choices about how (and where) they wanted the last precious weeks to be.

In most regions, however Aboriginal people and Torres Strait Islanders have poor access to palliative care services. Although the specific reasons for this may vary from State to State and region to region, there are a number of common factors that are widely experienced throughout Australia.

10.1.1 Variations in delivery and experience of palliative care

The experience of individuals and families is influenced by a variety of significant factors, including:

- models of service delivery vary in each State and Territory, and in some cases from region to region. Hospital or hospice care usually complements home care to some extent, but the way these elements are combined varies (see Chapter 2);
- diversity of Indigenous peoples and families and their social and cultural circumstances, which vary from region to region and between States and Territories (see Chapter 3);
- the health services available to Aboriginal and Torres Strait Islander peoples varies in different regions – for example, some areas are serviced by community controlled Aboriginal medical services; others may have only mainstream medical services (see Chapter 2); and
- the quality of palliative care available varies and depends on the capacity and willingness of service providers to ask and to listen (see Chapter 5).

10.1.2 Lack of knowledge of palliative care and what it means

In general, Indigenous people have not heard of palliative care, or if they have heard the term they understand it only to mean going to a nursing home, hospital or hospice (see Chapter 4, Section 4.4).

Indigenous people are not generally aware of the different kinds of palliative care services available (eg, home based care, pain management, access to special equipment, changes in the home, etc) (see Chapter 4, Section 4.4).

There may be a perception amongst service providers and in the wider community that palliative care is only for people who have cancer. Not enough attention is given to the special needs of Indigenous people with other life-limiting conditions, including those with kidney disease, respiratory disease and heart conditions (see Chapter 4, Section 4.4.1).

10.1.3 Factors contributing to lack of access to palliative care services

Mainstream and Indigenous health service providers tend to work ‘in parallel’ and often do not relate to each other. They may be unaware of how the other providers operate, what services they provide, and how they could work together (see Chapter 4, Sections 4.3 and Chapter 7 Section 7.3).

Palliative care services are generally provided by mainstream service providers which often do not have knowledge of, or relationships with, Aboriginal and Torres Strait Islander health services, community networks or Aboriginal and Torres Strait Islander cultures (see Chapter 4, Section 4.4 and Chapter 5, Section 5.4.2).

Indigenous people may not be referred to palliative care services by their health service or may not receive the support they need to understand medical information and information about palliative care (see Chapter 4, Section 4.3).

Indigenous patients are often diagnosed quite late in their illness and as a result are referred to palliative care services at a late stage (see Chapter 4, Sections 4.3.3 and 4.4.5).

Palliative care workers are likely to have had little contact with Indigenous communities and may have difficulty developing good relationships with Indigenous clients, especially if the client is referred late, and they may not understand or appreciate cultural differences. This will not only impact on their capacity to deliver effective palliative care services but will discourage Indigenous people from using or seeking out their service (see Chapter 4, Section 4.4.10).

10.1.4 Education of medical practitioners and health services

General practitioners and specialist doctors may not be aware of palliative care services and the benefits they could offer their patients. Education is needed to increase doctor awareness and encourage earlier referral to palliative care. GPs may not be aware that referral to palliative care does not mean that they have to stop caring for their patient (see Chapter 7, Section 7.6.1 and Chapter 4, Section 4.3.2).

Aboriginal and Torres Strait Islander community controlled health organisations (and other Aboriginal and Torres Strait Islander Health Services) need education about palliative care and its benefits, and how they can get help for their clients from palliative care specialists (see Chapter 7, Section 7.6.2 and Chapter 4, Section 4.3.2).

Indigenous health workers (Aboriginal hospital liaison officers, Aboriginal primary health workers and HACC workers) need training and awareness programs about palliative care and palliative care services in their State and their own regions (see Chapter 6 and Chapter 7, Section 7.4). Other Aboriginal and Torres Strait Islander health professionals including nurses, psychologists and doctors may also benefit from such programs.

10.1.5 Issues for palliative care policy makers and service providers

There are a number of issues and areas of need where policy makers could initiate action and/or palliative care service providers could provide advocacy on behalf of Aboriginal and Torres Strait Islander clients.

- Housing (eg, ability to relocate a patient during the period of palliation, or relatives after a death in the family) (see Chapter 5, Section 5.3 and 5.9.3).
- Ensuring that palliative care and Indigenous health providers are involved in hospital discharge planning (see Chapter 4, Section 4.3.6 and Chapter 5, Section 5.2.1).

- Development of ‘tagging’ or registrations systems that ensure that palliative care clients admitted to emergency wards are identified on arrival and are not given inappropriate treatment. This is especially important for Aboriginal and Torres Strait Islander clients who might not ‘speak up’ about what they need (see Chapter 5, Sections 5.6 and 5.9.3).
- Changes in hospital facilities and practices:
 - attitudes and expectations;
 - appropriate spaces for visitors;
 - allowing space and time for families to be with the deceased if it is required; and
 - design of palliative care facilities that can meet the cultural needs of local Indigenous people (see further Chapter 5, Section 5.3.3/4).
- Development of culturally appropriate grief and loss counselling strategies and services (see Chapter 5, Section 5.5).

10.1.6 Lack of resources

There are insufficient resources for the provision of palliative care services to Aboriginal and Torres Strait Islander people and there are some major gaps in the services that are provided. (see further Chapter 9). For example, there are regions where:

- there is no home-based care;
- services exist but they are not provided on a 24 hour basis;
- services exist but home-based care is not available on weekends;
- funding for personal care and home help services is inadequate, and they are not funded to provide palliative care and sometimes have to ‘close their books’ to palliative care clients;
- funding for purchase of equipment is inadequate;
- there is funding for equipment, but no funds for transporting it;
- there is no funding for Aboriginal and Torres Strait Islander liaison positions;
- the local Aboriginal medical service does not operate on a 24 hour basis, or does not provide home-based care; and
- there is no Indigenous-specific counselling service.

Availability of palliative care specialists may be inconsistent. Where available, specialist knowledge and skills are highly valued (see Chapter 5, Section 5.8).

Funding needs to be flexible so that palliative care packages can be purchased where needed (eg additional resources to allow people to be cared for in a remote community or in an aged care facility), or so that Indigenous staff with palliative care training or relevant cultural knowledge can be bought in (see Chapter 9, Section 9.2.7).

10.1.7 Lack of palliative care training

There is an urgent need for development and provision of training for Aboriginal health workers, for example, by including a component in undergraduate courses and/or creating post graduate certificate courses in palliative care and in mental health and bereavement (see Chapter 7, Section 7.5).

There is an urgent need for trained Indigenous psychologists and mental health workers to provide support or counselling in grief and loss (see Chapter 7, Section 7.5).

10.1.8 Indigenous employment in palliative care

There is a need for mainstream palliative care services to employ Aboriginal and Torres Strait Islander health workers who have received training in palliative care or to be able to broker in services from Indigenous health services. These skills could also be provided through consultancy arrangements with local Indigenous health services (see Chapter 6, Section 6.6).

There is a need for medically trained Indigenous advocates (such as Aboriginal health workers, enrolled nurses, registered nurses) to be employed by hospitals, health services and/or brokered in by palliative care services (see Chapter 6, Section 6.6).

There is a need for adequate supervision and debriefing of Aboriginal and Torres Strait Islander staff working in palliative care, particularly where staff are related to the deceased (see Chapter 5, Section 5.5.7).

10.1.9 What community members want

Early information and support (see Chapter 5, Section 5.5.7).

More information about life-limiting illness, the course of the illness and what to expect, especially at the final stage (see Chapter 7, Section 7.2).

More information about the services that are available (see Chapter 7, Section 7.1).

Respite care, both in the home and short-term residential (see Chapter 5, Section 5.4.2).

10.2 Implications for the National Strategy

The brief (see Chapter 1 Section 1.1) called for identification of '*areas that could be enhanced or developed under the National Palliative Care Strategy*' (NPCS) (2000). An analysis of the Strategy indicates a general congruence between the current National Strategy and the needs and issues identified during this scoping study.

The Strategy has three major goals, each with a number of objectives:

Goal 1: Awareness and understanding

Goal 2: Quality and effectiveness

Goal 3: Partnerships in care

Objectives under Goals 1 and 3 have the greatest levels of congruence. Some aspects of the objectives under Goal 2 are potentially problematic.

Some of the strategies should be strengthened or added to and it may be appropriate to develop a set of outcomes for Indigenous palliative care which mirror or can be set against the objectives. The areas for attention following on from the findings of this study are detailed below.

10.2.1 Goal 1: Awareness and understanding

There are major issues regarding lack of awareness and understanding of palliative care in Aboriginal and Torres Strait Islander communities. These were discussed in Chapter 4.

Objective 1.1: Community awareness and capacity

Devise strategies aimed at developing word of mouth information implemented through key members of Aboriginal and/or Torres Strait Islander communities. The strategy should include information, training and education for Aboriginal liaison officers, Aboriginal health workers and Aboriginal HACC workers, and should be supported by appropriate printed information for the community (see further Chapter 4, Section 4.6).

Objective 1.2: Families and communities of care

Develop a strategy which will deliver the specific sorts of information identified as needed by Indigenous community members. For example, the information booklets prepared by the Palliative Care Associations of South Australia and Western Australia provide a useful framework and should be reviewed and reproduced for Indigenous audiences with the inclusion of some additional practical information (see further Chapter 7 Section 7.2.2).

A number of Aboriginal and Torres Strait Islander people spoke of their desire for support groups for families coping with the life limiting illness of a family member. A number of people were interested in becoming volunteers within their own communities. No mainstream volunteer programs have previously recruited within Indigenous communities. There is scope for these programs to be made more effective, however coordinators of volunteer programs would need cultural awareness training and guidance from Aboriginal and/or Torres Strait Islander advisors about recruiting within Indigenous communities (see further Chapter 7 Section 7.9).

Objective 1.3: Professional awareness

Develop strategies aimed at government and community-controlled Aboriginal health services to develop the awareness of health professionals working in them (doctors, nurses and health workers) about palliative care. These groups should be specifically targeted and included in programs such as GP palliative care education. The support of NACCHO, OATSIH, and bodies such as CATSIN and AIDA should be enlisted. (see further Chapter 7 Section 7.6).

Aboriginal Health Worker undergraduate training should include a palliative care component to explain what palliative care is and to explain what services are available in each State. (see further Chapter 7 Section 7.1.3).

The peak organisations representing other Aboriginal and Torres Strait Islander health professionals such as nurses, psychologists, social workers and doctors should be engaged to assist in the development of information strategies aimed at increasing professional awareness (see further Chapter 7 Section 7.6.7).

Objective 1.4: Professional education

Consideration should be given to strengthening this objective by specifically mentioning Aboriginal and Torres Strait Islander health professionals (nurses, psychologists, social workers, doctors and Aboriginal health workers). There is a defined need for a post graduate certificate in palliative care for health workers, and a need for a component on grief and loss associated with palliative care in the Mental Health Certificate (see further Chapter 7 Section 7.6.1-7.6.2).

As well, professional development curricular for GPs, nurse practitioners and registered nurses in the Aboriginal and Torres Strait Islander health sector need to include issues related to palliative and bereavement care. For GPs this could be facilitated through CME programs coordinated by professional

colleges, and for nursing graduates, through the development of specific post graduate certificate level courses. A specific module on Indigenous issues in palliative and bereavement care should be included in undergraduate training curricula for all doctors and nurses as part of their education in Indigenous health.

Mainstream palliative care workers need specific cultural awareness training, tailored for palliative care workers, which will translate into effective cross cultural practice. Such training must go beyond awareness to deliver competencies in practice in cross cultural environments. Cultural awareness courses for palliative care workers need to be revised to deal with issues of death and dying for Aboriginal and Torres Strait Islander people and to provide safe learning environments where practitioners can review their own belief and value systems and communication practices. Such courses need to deliver cognitive change not just awareness. Professionals delivering care at home need special skills in developing relationships with the local Indigenous community and with individual clients. This is critical given the high frequency of late referral of Indigenous clients to palliative care. (See further Chapter 7, Section 7.7)

In the first instance, this education might look at basic issues of developing cross-cultural partnerships with Indigenous organisations in the community. Such education could be attended by both mainstream palliative care organisations and Aboriginal and Torres Strait Islander health services in each local region.

Objective 1.5: Awareness at policy level

This objective should be strengthened to encourage policy makers at State and Australian Government levels to consider and incorporate palliative care for Indigenous clients in policy and funding documents (eg State / Indigenous health partnerships, state strategic plans and OATSIH funding formulas). The challenge here is not only to raise awareness of policy makers about palliative care for Aboriginal and Torres Strait Islander peoples but to do so in such a way as to ensure that local Aboriginal and Torres Strait Islander communities will be engaged in advising on their particular needs. Decision makers in ACCHS and State-run Aboriginal and Torres Strait Islander Health units must be specifically targeted (See further Chapter 7, Section 7.6.6).

10.2.2 Goal 2: Quality and effectiveness

Objective 2.1: Standards

This strategy must be approached with extreme caution. Practice standards must be reviewed to check their applicability to all Indigenous situations. In some cases the best palliative care for a person may involve their return to an environment which would not be regarded as meeting medical or personal care standards. Practice standards developed must give due weight to emotional, social, cultural and spiritual issues. From an Indigenous perspective, an initial starting point for any standard may be that a local Indigenous cultural broker or patient advocate, acceptable to both patient and family, is included in palliative care planning for Indigenous patients. Standards are discussed further in Chapter 8, Section 8.5.

Willis (1999) states *'the issue is not simply to modify elements of palliative care so that cultural differences in belief and practice around death are accommodated, but to recognise that different cultures 'do death' in different ways, and that institutions for the provision of palliative care are bound up in the 'way of dying' of the culture in which they originated.'* (p 427). He goes on to discuss the concept of a 'good death' (as defined in terms of modern hospice practice), as opposed to what he terms an 'acceptable death' (p 434) as defined in terms of the desires and expectations of the patients and their families. The implication is that one person's 'good death' may be another person's 'bad death'. Willis also points out that changing minor details of service delivery such as food or the numbers of visitors, or the time allowed for visits

(though they may be necessary) are inadequate responses to cultural differences in the underlying assumptions of care.

The setting of standards in relation to these matters is not simple.

Whilst it may not be practicable to set prescriptive standards for the delivery of culturally appropriate palliative care, it should be possible to set standards for appropriate cross cultural communication and practice. These should ensure, for example: effective input into policy and cross cultural practices by appropriate Indigenous organisations; employment or participation of Indigenous staff where possible and appropriate; effective communication between Indigenous and non-Indigenous service providers, and so on. Ultimately the effectiveness of such standards would need to be determined by consumers – palliative care clients and their families – so observance of these standards would need to be monitored or measured by (culturally knowledgeable) third party interview of consumers.

This objective suggests that resources should be tied to good practice. There is a danger that tying resource allocation to good practice will disadvantage those who are already disadvantaged. At the same time, bad practice should not be fostered simply because of a practical absence of better alternatives. Where consumers are not well served by existing services, action needs to be taken (and resources applied) to ensure that those services are improved (or replaced) rather than withdrawn because they do not meet standards. Services should be strongly encouraged to develop local models of good practice for Aboriginal and/or Torres Strait Islander patients, in partnership with other local service providers in Aboriginal and Torres Strait Islander health or palliative care.

Objective 2.2: Resource allocation and administrative support

This objective should explicitly recognise that some culturally determined costs which in the past may not have been seen as the province of palliative care funding should be recognised as legitimate palliative care costs (see also Chapter 9). These may include costs for:

- temporary housing for the duration of the palliation (for cultural and/or socio-economic reasons);
- transport to take the client home (with adequate care);
- locating and accessing traditional healers;
- return of deceased to their home country or community; and
- providing support or assisting with funeral arrangements as an essential part of bereavement.

Objective 2.3: Accountability and reporting

The administration of the Indigenous status question in relation to palliative care clients is a major issue, not only for consistent reporting and monitoring but also for delivery of appropriate care. Our research shows that the question is often not asked, but is assumed in many health admissions and that most palliative care assessment processes do not usually ask or record this information (see further Chapter 4). While most palliative care assessment instruments ask clients about cultural issues, most do not ask about Indigenous status. There are often poor links between systems that record Indigenous status information and systems that record palliative care.

Objective 2.4: Service development

A number of our findings are likely to have implications for this very broad and all-encompassing objective. Some immediate additions are obviously needed, such as the addition of end stage renal disease to Strategy 2.4.4 of the National Palliative Care Strategy (NPCS) (see further Chapter 4, Section 4.5).

The relevance of some of the strategies to Indigenous issues should perhaps be highlighted. For instance, the development of palliative care pathways (NPCS Strategy 2.2.3) (particularly incorporating referral processes) would allow the triggering of appropriate cultural support and advocacy at key times (see further Chapter 5, Sections 5.9.3 and 5.6.5). The use of video-conferencing (NPCS 2.4.4) has particular relevance to remote Aboriginal and Torres Strait Islander peoples. Early tele-medicine conferencing should help prevent unnecessary transfer of remote patients to city hospitals, and use of video conferencing to facilitate family access and family meetings for remote community members is very important. This might also be used in Aboriginal-specific nursing homes on the east coast where relatives live long distances away, but most AMSs have video conferencing equipment which families could access (see further Chapter 5, Section 5.9.4).

There is a need for effective quality control and improvement. Specifically mainstream palliative care providers should develop systems to check on the quality of their service to Aboriginal and Torres Strait Islander clients. A program of service review conducted six months after a death and using an Indigenous reviewer would be a useful way for services to discover how their services could be improved (see Chapter 8, Section 8.5.2).

Some specific targets or outcomes could be developed in relation to NPCS Strategy 2.4.5.

Objective 2.5: Research and evaluation

Section 10.3 below identifies several particular target areas for research. One relates to the delivery of 'bad news' by doctors and another to research into the best approaches to grief and loss and the development of effective treatment programs for Aboriginal and Torres Strait Islander clients. Research into competencies to be delivered by effective cultural awareness training and into the development of palliative care pathways is also needed.

10.2.3 Goal 3: Partnerships in care

Objective 3.1: Partnerships in care coordination

This goal requires an introductory objective about raising the profile of mainstream service providers within Indigenous communities, including naming specific individuals as contact persons for Aboriginal and/or Torres Strait Islander clients and services, so that relationships can be developed and to facilitate care planning. Such relationships currently do not exist in most places, however before partnerships can develop, basic relationships need to be in place to establish a basis for trust. A preface to this effect should be added to this goal. (See further Chapter 5, Sections 5.4.2 and Chapter 7, Section 7.3)

A number of protocols then need to be developed on a local and regional basis to facilitate the development of care planning (eg see guidelines in Appendix 12).

Objective 3.2: Partnerships in service planning and delivery

Issues that are relevant here include the need for local relationships and partnerships and the need for Aboriginal and/or Torres Strait Islander staff (see further Sections 4.3 and 7.3 and Appendix 12).

Local planning workshops are needed so that Indigenous health and home care services can find out what palliative care services do, and vice versa, and then work out how they can best work together. Local colleges of GPs should be involved in these workshops.

Palliative care services need to employ trained Aboriginal and/or Torres Strait Islander staff to assist in the development of their services. These positions are needed at State level (in government and/or in Palliative Care Associations) and in services in regions with high Aboriginal and Torres Strait Islander populations. Two types of positions are envisaged although in some places they may be combined: *Development positions*¹ which primarily aim to develop services within a region and *Service Delivery positions* which would work more directly with clients. Sufficient trained Indigenous palliative care positions (or days) need to be funded so that these services can be bought in as needed. A strategy more specifically directed at Indigenous employment may have resulted in this issue being dealt with, or at least pointed out, in the Palliative Care Australia Planning Guide (2002). (See further Chapter 6, Section 6.6, Chapter 7 and Appendix 14.)

Objective 3.3: Partnerships in policy development

Much of the comment above in relation to Objectives 3.1 and 3.2 applies to this objective, but at State and Australian Government level. Employment of Indigenous palliative care development staff in key places will ensure that policy makers engage with palliative care issues. Until now, most Indigenous health bureaucrats (State, Australian Government and in the community controlled sector) have not been well informed about palliative care and as a result it is not raised in policy development (see also Objective 1.5 above in Section 10.2.1).

10.3 Conclusions

The implications of the findings of our study are recorded in more detail within the relevant chapters of this report (as cross referenced above) and these sections should be considered by service providers and policy makers. Some of the immediate and medium term actions needed and some key targets are outlined below.

10.3.1 Demonstration projects and resource shortfalls

It is clear that an infusion of funds is required in the short term to:

- develop the capacity of Aboriginal and Torres Strait Islander communities to access and take part in delivery of palliative care services. Immediately, training for Aboriginal and Torres Strait Islander health workers, nurses, psychologists, social workers, doctors and allied health professionals is needed.
- develop services to provide culturally sensitive delivery of palliative care by improving the design and coordination of services, employing Aboriginal and Torres Strait Islander staff and improving the cultural competence of mainstream staff. Coordination must involve ACCHS and/or Area Health Boards.

This process could be 'kick started' by the establishment of a number of demonstration projects, some at State or regional level and some at a local, hands on level. Such projects should give high priority to training issues and planning and coordination.

It is estimated that 5 years' funding is required to develop pilot and demonstration projects which will set up the infrastructure so that the States and Territories could deliver needed services in a prioritised way.

¹ See Appendix 14 Model Duty Statement – Indigenous Palliative Care Development Worker.

A mechanism by which these projects might be managed may be the establishment of a committee of each of the State or Territory Partnership Forums to develop State palliative care strategies for Aboriginal and Torres Strait Islander peoples. These committees could use the demonstration projects to develop models of coordination and service delivery and at the same time identify resource shortfalls on a regional basis. Clearly the community controlled health sector will have to be involved in this process.

It is extremely important that the non-government sector (for example the Palliative Care Associations and the Cancer Foundation) and are involved in and take some ownership of this process.

10.3.2 Some key targets

Many of these targets are relevant to other culturally and linguistically diverse groups as well as to Indigenous peoples.

Employment and training of Aboriginal and Torres Strait Islander staff to work in palliative care

This should be a central target and is discussed in Chapters 6 and 7.

Information strategies

Communication strategies for Aboriginal and Torres Strait Islander communities and for decision makers working in Aboriginal and Torres Strait Islander health are discussed in Chapter 7.

GP and AMS doctor education

It is extremely important that GPs who work with Aboriginal and Torres Strait Islander clients² have the opportunity to learn more about palliative care and cultural issues surrounding death and dying. It is important that AMS doctors come to see palliative care as a special service which they can access for their clients and in which they can take a central role. It is suggested that a Continuing Medical Education (CME) package on these issues be developed for GPs. Assistance might be sought from the College of General Practitioners to sponsor such programs in areas of high Aboriginal and Torres Strait Islander population (see further Chapter 7).

Cultural and linguistic advocacy

All palliative care teams should have the capacity (in service delivery design and resources) to engage cultural advocates for their clients (both Indigenous and Culturally and Linguistically Diverse (CALD) clients). Cultural advocates need orientation in the objectives and methods of palliative care (especially respect for the individual's wishes) as well as cultural awareness training (in respect of the mainstream medical culture in which they will be working). Cultural advocates should receive supported debriefing as part of their engagement.

All palliative care services should have the capacity to engage the services of language interpreters where the family involved does not speak English. The implication of this is that funding is needed for brokering in these services and in some places may be needed to establish them (eg a service offering various Aboriginal languages in Perth). These interpreters will require the same orientation as cultural advocates and should receive supported debriefing as part of their engagement. (See further Chapter 3, Sections 3.2.8 and 3.3.2.)

² including those who work in ACCHS or AMSs, and those who work in regions with high Aboriginal and/or Torres Strait Islander populations.

Cultural awareness training

All palliative care workers and community nurses should have regular cultural awareness training and related work experience opportunities to develop competence in cross cultural communication. Cultural awareness training needs to be developed to deliver effective cross cultural communication and practice as well as to deal with issues specifically related to Indigenous death and dying. Cultural awareness training of hospital staff should be reviewed and improved, especially where large numbers of agency staff are used in areas of high Aboriginal and Torres Strait Islander population (see Chapter 7).

Hospital and hospice design and management

Chapter 5 outlines some key issues for hospital and hospice design and management in relation to Aboriginal and Torres Strait Islander people. These issues have wide applicability in the Australian context. Many of the needs regarding facilities at the time of death identified by members of Aboriginal and Torres Strait Islander communities are applicable to other culturally and linguistically diverse groups.

Research targets

Four areas of research need present themselves:

- State or regionally-based research into how ‘bad news’ is usually delivered, how it should be done, the roles of family and cultural supporters, and links between the initial or subsequent advice of diagnosis and follow up actions, such as referral to palliative care. The way in which ‘bad news’ is delivered is critical to Aboriginal and Torres Strait Islander people accessing palliative care services. People need to be told in a way that is appropriate to their culture and in a way that will support them in making informed choices about their future options. What is appropriate will vary from place to place (see Chapter 4). Bodies representing Indigenous health professionals such as nurses (CATSIN), doctors (AIDA), psychologists and social workers should be consulted in the development of this research;
- Contemporary Aboriginal and Torres Strait Islander modes of dealing with grief and loss, and the development of effective and accessible methodologies and programs in this area (see Chapter 5, Section 5.5);
- A review of the effectiveness of cultural awareness training and development of competencies in cross cultural communication and service delivery (see Chapter 7); and
- Development of model palliative care pathways which include checkpoints for cultural advocacy and cultural safety (see Chapter 5, Sections 5.6 and 5.9.2).

10.3.3 Immediate actions that would help increase Indigenous people’s access to palliative care

- Initiate a dialogue between mainstream and Indigenous service providers in your region or local area to find out what each does, what each has to offer and to work out how the gaps can be filled. The solutions should be developed in response to local circumstances and cultural needs. This action can be taken by individual service providers and/or Indigenous health services. It should be encouraged and supported by State governments and non-government associations.
- Development of an Aboriginal and Torres Strait Islander palliative care network and ongoing Indigenous palliative care newsletter.
- Employ Aboriginal and Torres Strait Islander people in local palliative care services (see model duty statement, Appendix 14).
- Schedule a planning workshop for the region involving all relevant parties.

References

- (2000). *National Palliative Care Strategy: A National Framework for Palliative Care Service Development*, Commonwealth Department of Health and Aged Care.
- (2002). *Palliative Care Service Provision in Australia: A Planning Guide*. (PCA). Palliative Care Australia.
- Willis, J. (1999). 'Dying in country: implications of culture in the delivery of palliative care in Indigenous Australian communities.' *Anthropology and Medicine* 6(3): 423-435.

Appendix 1

Questionnaire sent to all service providers
on the Palliative Care Australia
mailing list

Reply Paid 81
Kate Sullivan & Associates
22 Waterview Street
Balmain, NSW 2041
email - project@telpacific.com.au
Phone - 02 9810 5755
Free Phone - 1800 810 234
Fax - 02 9818 4528

Dear Palliative Care Service Provider,

The enclosed Newsletter describes the Indigenous Palliative Care Scoping study that we are undertaking for the Australian Government Department of Health and Ageing.

We would very much appreciate your answering some questions for us about your service.

Rather than fill in the slip on the newsletter could you please complete the following questions and post them to the **Reply paid** address above. If you do not have Indigenous clients the list of questions is very short! We would be pleased to receive the question sheet by the end of April.

Sincerely,

Kate Sullivan
Executive Director

2.4.02

Indigenous Palliative Care Scoping Survey

Organisation Name: _____	Demographic: <input type="checkbox"/> Indigenous <input type="checkbox"/> Mainstream
Branch/Section: _____	Loc Type: <input type="checkbox"/> urban <input type="checkbox"/> rural <input type="checkbox"/> remote
Address: _____	Coverage: <input type="checkbox"/> State
_____	<input type="checkbox"/> Regional or <input type="checkbox"/> Local

City: _____	Contact Details: _____
State: _____	Title: _____ First Name: _____
Post Code: _____	Last Name: _____
	Position: _____
Post Address Details: _____	Phone: _____
Address: _____	Fax: _____
City: _____	Email: _____
State: _____ Post Code: _____	

Question 1

1. Do you record the Indigenous status of your clients (eg do you record if they identify as an Aboriginal person, or a Torres Strait Islander or both an Aboriginal person and a Torres Strait Islander?)

a. Yes / No (*please circle*)

b. If yes. How is this question administered?

i. Is each person asked the question? (please tick) OR

ii. Is the answer assumed or guessed? (please tick)

2. Do you know how many Aboriginal or Torres Strait Islander clients accessed your services in the last financial year?

• Yes / No

• How many?

3. How (and by whom) were these clients referred to your organisation?

4. Do you have any regular contacts with the local Aboriginal or Torres Strait Islander communities or organisations?

a. Yes / No (*please circle*)

b. What form has this contact taken?

5. Have you made contact with the Aboriginal Liaison Officer in your local hospital/s?

Yes/No (*please circle*)

6. Do you know how many Aboriginal and/or Torres Strait Islanders live in the catchment area serviced by your organisation? Please state either:

• the approximate number if you know it OR

• whether the Indigenous population is relatively Small, Medium or Large, (please circle) OR

• state that you don't know (*please tick*)

If you answered No and None to question 2 above, please post this sheet only to the reply paid address. If you answered Yes and More than one, to question 2 please complete the rest of the questions below (ie indigenous Service Provider questions).

Only complete questions 2-10 if you have Indigenous clients

Question 2

2a Is your service Mainstream or Indigenous?

- Indigenous Mainstream

2b Is your service a Government or Non-Government organisation?

- Government Non – Government

Question 3

3a What services do you provide? (*please tick*)

- | | | |
|---|---|---|
| <input type="checkbox"/> Hospital | <input type="checkbox"/> Funeral Services | <input type="checkbox"/> Facilitates access to traditional medicine |
| <input type="checkbox"/> Clinic | <input type="checkbox"/> Funeral Funds | <input type="checkbox"/> Facilitates access to traditional law and spiritual support |
| <input type="checkbox"/> Hostel | <input type="checkbox"/> Pain Management | <input type="checkbox"/> Facilitates traditional mourning and/ or cleansing practices |
| <input type="checkbox"/> Hospice | <input type="checkbox"/> Respite Care | <input type="checkbox"/> HACC workers |
| <input type="checkbox"/> Nursing Home | <input type="checkbox"/> Housekeeping/ home help | <input type="checkbox"/> Community Aged Care Packages |
| <input type="checkbox"/> Bereavement/ Grief Counselling | <input type="checkbox"/> Carer Support | <input type="checkbox"/> Aboriginal Medical Service |
| <input type="checkbox"/> Advocacy | <input type="checkbox"/> Voluntary Carer Arrangements | <input type="checkbox"/> Service Provider Network |
| <input type="checkbox"/> Transport | <input type="checkbox"/> Disease Specific Medical (.....) | <input type="checkbox"/> Network/ Support Group |
| | | <input type="checkbox"/> Other (.....) |

3b Would you regard any of these services as examples of ‘best practice’ ie culturally sensitive and effective? Please describe.

(Please use additional pages if needed)

Question 4: Number of palliative care clients?

4a

Total (Fin Year) 2000/2001 clients:

% Aboriginal and Torres Strait Islander:

% Aboriginal:

% Torres Strait Islander:

% Indigenous PC clients by age	% Non-Indigenous PC clients by age
0 – 10:	0 – 10:
11 – 20	11 – 20
21 – 30	21 – 30
31 – 40	31 – 40
41 – 50	41 – 50
51 – 60	51 – 60
61 – 70	61 – 70
71 – 80	71 – 80
80+	80+

4b Total current Indigenous palliative clients:

Question 5: Source of palliative care funding

Percentage	Type of funding (AHCA, HACC, Flexible, Multipurpose etc)
Australian Government Health:	
State Government:	
Local Government:	
AMS:	
ATSIC:	
Community:	
Church:	
Charity/Not For Profit	
User Pays:	
Other:	

Level of Palliative Care Funding (Annual Budget) \$:

If these questions do not fit your situation please describe your funding arrangements on a separate sheet.

Question 6

Number of staff	Male staff		Female staff	
	Indigenous	Non - Ind	Indigenous	Non - Ind
Management:				
Admin:				
Doctor:				
Nursing:				
Health Worker:				
Advocate:				
Community Liaison:				
Driver:				

Number of Staff with Cross Cultural Training:

Number of Staff with Palliative Care Training:

Number of Staff with Indigenous Palliative Care Training:

Question 7

What other types of Palliative Care are there in the region/area and who provides them?

Indigenous or mainstream? [I / M]

Type of service	Location	Organisation	Contact Phone	I / M

Question 9

What do you think are the major future issues in Indigenous Palliative Care?

Question 10

What do you think are the major needs in regards to policy, planning or practice in Indigenous Palliative Care?

Question 11

What do you think are the major unmet needs in Indigenous Palliative Care?

Question 12

Is there anyone else that you think we should talk to including Non-Government Organisations?

Contact Name	Contact Phone	State	Organisation	Notes

Question 13

Is there anything that has been written that we should read?

Title	Author	Journal/Publisher	Date

Question 14

a. In relation to working in palliative care would you describe yourself as:

- Very experienced Somewhat experienced Relatively new or inexperienced

b. What about working with Aboriginal and Torres Strait Islander palliative care clients?

- Very experienced Somewhat experienced Relatively new or inexperienced

c. Do you identify as an:

- Aboriginal person Torres Strait Islander
 Aboriginal & Torres Strait Islander person Non – Indigenous Person

Please post to the reply post dress on the front of the form

Appendix 2

Results of questionnaire sent to all
service providers on Palliative Care Australia
mailing list

Question 1

Do you know how many Aboriginal or Torres Strait Islander clients accessed your services in the last financial year?

Numbers of Indigenous clients	0	1	2-5	5-10	10-20	20+	Total Responses
Number of responses	46	12	19	3	2	1	83 ie 29.3 %

How (and by whom) were these clients referred to your organisation?

	Referrer	Frequency
	GP	25%
	Hospital	21.88%
	AMS /ICCHO	17.19
	Community health centre	9.4%
	Self	9.4%
	Aged care hostel	6.25
	Nurses	3.13
	PC or service provider	3.13
	Family/friends	3.13
	Less than 2 Indigenous Clients last year	More than 2 Indigenous Clients
Do you record the Indigenous status of your clients a. a. Yes / No	86% yes	81 %yes
b. If yes. How is this question administered? i. Is each person asked the question? OR ii. Is the answer assumed or guessed?	85% asked rather than assumed	86% asked rather than assumed
Do you have any regular contacts with the local Aboriginal or Torres Strait Islander communities or organisations? a. Yes / No (<i>please circle</i>) b. What form has this contact taken?	29% yes <i>Mostly by meeting and mostly with ALOs and occasionally with AMS</i>	63% yes <i>Mostly by meeting and mostly with ALOs and occasionally with AMS</i>
Have you made contact with the Aboriginal Liaison Officer in your local hospital/s? <i>Many who answered NA said that this was because they did not believe that there was an ALO at the local hospital</i>	29% yes 48% no 25% NA	59% yes 41% no
Do you know how many Aboriginal and/or Torres Strait Islanders live in the catchment area serviced by your organisation? Please state either: <ul style="list-style-type: none">the approximate number if you know it ORwhether the Indigenous population is relatively Small, Medium or Large, (<i>please circle</i>) ORstate that you don't know - Yes / No	42% small 16% medium 42% don't know	30% small 35% medium 25% large 10% don't know

Summary of Issues and Needs from responses to Questionnaire sent to all Service Providers on Palliative Care Australia mailing list (see Appendix 1)

Best Practice

- Where AHWs are used, consulted and assist with care and coordination
- Consultation of elders and family members
- Evidence based professional care
- Actions guided by client and family needs
- Sensitive to individual needs – Ask what is needed and seek assistance to obtain care through appropriate services (eg local Aboriginal health staff)
- Care in the home situation which enable extended families to participate and assist with the care
- Provision of individualised care – meeting the values and beliefs of the individual. PC Service provider contacts Indigenous support services – (liaison person or health centre) as appropriate.

Indigenous staff

None of the mainstream services who responded had any indigenous staff except for one HACC service which had a part-time Indigenous worker put on especially to deal with a 'difficult client'

One Indigenous health service which replied (Qld Govt funded) commented that they could not provide palliative care because they had no trained staff)

Traditional practice

No particular information was obtained. Some responded that traditional practices would be used alongside western methods if this was wanted

Issues and needs

Many mainstream service providers stated that they could not comment: eg questions about future issues and needs they felt could only be answered by Indigenous people

The main issues that were raised are noted below:

Access Issues

- Lack of knowledge of palliative care services – need broad community education about what palliative care is
- Lack of access
- Fear of mainstream services
- Lack of trust in health care workers

Education and Training Issues

- Training to mainstream services by local indigenous population
- Education for all providers of palliative care about specific cultural needs re dying - who to contact for information etc.
- Mainstream providers need to understand need of Aboriginal clients who are often too shy to state their needs

- Lack of knowledge of Indigenous culture
- Knowing what Aboriginal families and carers would like of palliative care providers
- Increased cross cultural education
- More education for palliative care providers
- Need for cultural awareness programs that specifically address palliative care issues
- ‘Aboriginal advocacy is needed in the education of mainstream health providers so that together future needs and care provision can be implemented.’

Cultural and social Issues

- Conflict between what patient /client wants and what the wider cultural group wants
- Variety between patients ‘Need to be careful not to train people to think that all indigenous people are the same There is diversity in beliefs, values and practises.
- Limited grief and bereavement follow up due to transience of clients
- Family conflict in the home situation

Resources

- Not enough funding to cater to the needs of every group and individual – Management stresses equity of service.
- Funding for more RNs
- Funding for overnight respite needed

Service delivery issues

- Need user friendly or culturally appropriate services
- Cultural safety in planning and policy for operational practice
- Clarity and consistency in the role of AHWs and their interface with other members of the health care team.
- Service provider and family consultation PRIOR to DISCHARGE – major issues need to be discussed at this time.
- Increased access for Aboriginal workers in medical field
- Indigenous health care workers struggling with care when mainstream help and support is available.
- Need better links with Indigenous Health Services
- Need to work with major stakeholders to ensure special needs are encompassed

Mainstream perspective issues

- Need for Aboriginal people to compromise
- Worker safety – *(the only instance of employment of Indigenous workers noted in these responses was motivated by workplace safety concerns for mainstream staff– not cultural safety concerns of client)*

Unmet issues

‘People who are in need of Palliative Care are usually admitted into the XX hospital. I believe that many of the clients would rather be looked after at home in the first instance than be taken to the hospital when they can no longer be managed at home.’ (Aboriginal health service)

Need an appropriate ward at the hospital

Ability to counsel family members

'as there are very few Indigenous staff (male or female) Health workers or nursing staff across Qld. those that are working in a health worker capacity need to be trained and educated on what palliative care is. When you are working in a team of about 7 health workers you can get a choice or change position regularly - however if you are only one worker, training is limited. Should be available for health workers in isolated areas.' (HW)

Appendix 3



Access rates

Access DATA

The responses from questionnaires and field interviews were recorded and compared with the 1996 ABS figures¹ on Aboriginal population. Using the Australia Post map² of post codes and the ABS population information, rough estimates were made of the Aboriginal population of the areas concerned. The data is presented on pages 2 and 3.

These figures are general approximations as there was no information about the catchment boundaries of the various services which responded. The ABS catchment boundaries do not coincide with postcode areas (the best data we had for the location of services).

The charts on pages 4-6 display the tabulated data. They show the ratio of admitted Indigenous palliative care clients (2000-2001) compared with the number of Indigenous people in the population of that region.

The data below falsify the following hypothesis: There are a few palliative care units with a percentage of Indigenous clients far greater than their incidence in the general population but for the vast majority of palliative care units, about which we have information, the percentage of Indigenous persons in the general population is much greater than that in palliative care units.

The ratio of Indigenous palliative care clients to Indigenous people in the population expected under the hypothesis that the incidence of Indigenous persons in the population is accurately represented in care is 1. 18 of the 78 replies are at or above this figure, 60 are below. In the vast majority of responses, (75%) Indigenous persons are under-represented in these care units.

¹ Population Distributions, Indigenous Australians – ABS 1996 Census data

² Official Australian Postcode Map. Produced by AUSLIG 1993

PERCENTAGES OF INDIGENOUS PEOPLE IN PALLIATIVE CARE IN 2000-2001 AND IN THE REGIONAL POPULATION

	In all care	In population
*I, indicates and Indigenous specific service. *IC, indicates and Indigenous community.		
ACT		
Barton (Hospice)	0.00%	0.84%
NSW		
Bega (Community Health Service PCS)	0.00%	1.80%
Grafton (Community Health Service PCS)	1.86%	3.80%
Hoxton Park (Comm HS PC)	2.95%	1.60%
* I Kempsey (Aboriginal Nursing Home) PC Clients	43.00%	13.54%
Kempsey (Community Health Service PCS)	2.40%	13.54%
Kogarah (PCS)	0.00%	0.33%
Lismore (Hospital PCS)	0.00%	2.50%
Mona Vale (PCS)	0.00%	0.33%
Mt Druitt (Hospice)	0.35%	1.50%
Newcastle (Hospital PCS)	0.00%	1.40%
Nowra (Community Health Service PCS)	1.33%	7.65%
Nth Sydney (Home nursing service)	0.00%	0.16%
WAHS (PCS)	0.18%	1.50%
Windsor (Community Health Services)	0.00%	2.00%
NT		
Alice Springs Region (PCS) (Darwin and Jabiru ABS catchments)	50.00%	16.74%
Darwin Region (PCS)	40.00%	15.70%
Alice Springs (Volunteer PCS)	0.00%	16.73%
QLD		
Allora (Nursing)	0.00%	1.87%
Brisbane - Windsor - (Hospice Services)	0.00%	1.27%
Brisbane (Children's Hospice)	8.00%	1.30%
Cairns (Home Volunteers)	12.50%	7.66%
Cairns (PC)	8.80%	7.66%
* I.C. Cherbourg (Hospital)	100.00%	94.00%
Labrador (Dom Care)	0.00%	1.73%
Logan/ Beaudesert (District HS PC)	0.10%	1.56%
Mt Isa (Nursing Service)	19.23%	19.44%
Pittsworth (Nursing)	0.00%	1.15%
Toowoomba (Nursing)	1.63%	3.15%
Toowoomba (Private Hospital PC)	0.00%	3.15%
Townsville (Hospital)	2.90%	4.90%
SA		
Adelaide (Hospice)	0.30%	0.90%
Adelaide (Hospital)	0.00%	0.90%
Adelaide (RDNS)	0.20%	0.90%
Minlaton (Community Health)	0.00%	1.60%
Mt Gambier (Com Health Service PC)	0.00%	1.50%
Naracoorte (Health Service)	0.00%	0.90%
Nth Adelaide (PCS)	0.30%	0.90%
* I Port Augusta (Aboriginal Nursing Home)	100.00%	13.49%
Port Augusta (PCS)	0.89%	13.49%

**PERCENTAGES OF INDIGENOUS PEOPLE IN PALLIATIVE CARE
IN 2000-2001 AND IN THE REGIONAL POPULATION**

	In all care	In population
VIC		
Bairnsdale (District Nursing)	0.00%	2.47%
Ballarat (HS PCU)	0.00%	0.70%
Broadmeadow (HS PCU)	0.00%	0.30%
Castlemaine (District Nursing)	0.00%	0.70%
Colac (Com HS PC)	0.00%	0.53%
Footscray (Hospital PCS)	0.00%	0.30%
Foster (District Nursing)	0.00%	0.40%
Heidelberg (PCS)	0.00%	0.30%
Horsham (Hospice Care)	0.00%	0.70%
Ivanhoe (PCS)	0.00%	0.30%
Kyneton (HS PCS)	0.00%	0.70%
Newcomb (HS)	0.00%	0.43%
Numurkuh (PCS)	0.00%	1.00%
Prahran (Private hospital and home based PC)	0.00%	0.30%
Shepparton (PCS)	3.30%	2.34%
Sunshine (Hospital)	0.00%	0.30%
Warrnambool (HS PCS)	0.00%	0.98%
Wodonga (District Nursing PC)	0.15%	0.73%
WA		
Albany (Hospital PC)	1.67%	1.30%
Albany (Nursing service)	4.00%	1.30%
Bridgetown (Hospital PC)	0.00%	1.19%
* I Broom (Aged Hostel)	50.00%	25.44%
Denmark (Health service)	0.00%	1.12%
Geraldton (PCS)	8.70%	8.00%
Kalgoorlie (Community carer support)	9.00%	5.93%
Kalgoorlie (Hospital PCU)	3.30%	5.93%
Karratha (Homecare)	20.00%	9.57%
Kimberley (Health Service/District hospital)	50.00%	34.70%
Manjimup (Health service)	0.00%	1.12%
Nannup (Health service)	0.00%	1.19%
Nth Midlands (Health service)	0.00%	5.00%
Perth (Hospice)	0.80%	1.40%
Perth (Hospice)	0.00%	1.40%
Perth (Hospital) Note that the catchment for this hospital is state wide	0.80%	1.40%
Perth (Hospital) State wide catchment*	1.80%	3.10%
Perth (PC nursing services)	0.80%	1.40%
* I Port Headland/Pilbara (Nursing Home health service)	80.00%	9.00%
Wagin (Hospital PC)	0.00%	6.40%

Chart1: All responses: Numbers 1-78

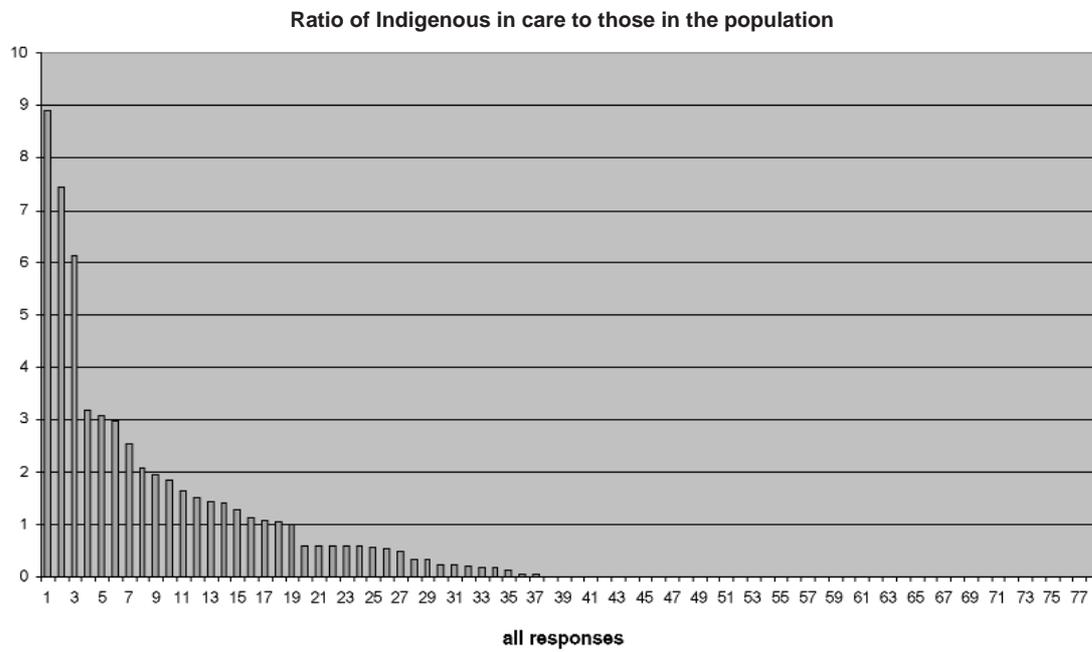


Chart A: shows the first 19 from the Chart 1, in more detail. (ie Numbers 1-19 of 78)

Three of the first four, and five of the whole 18 are Indigenous specific services. They are marked with a preceding I.

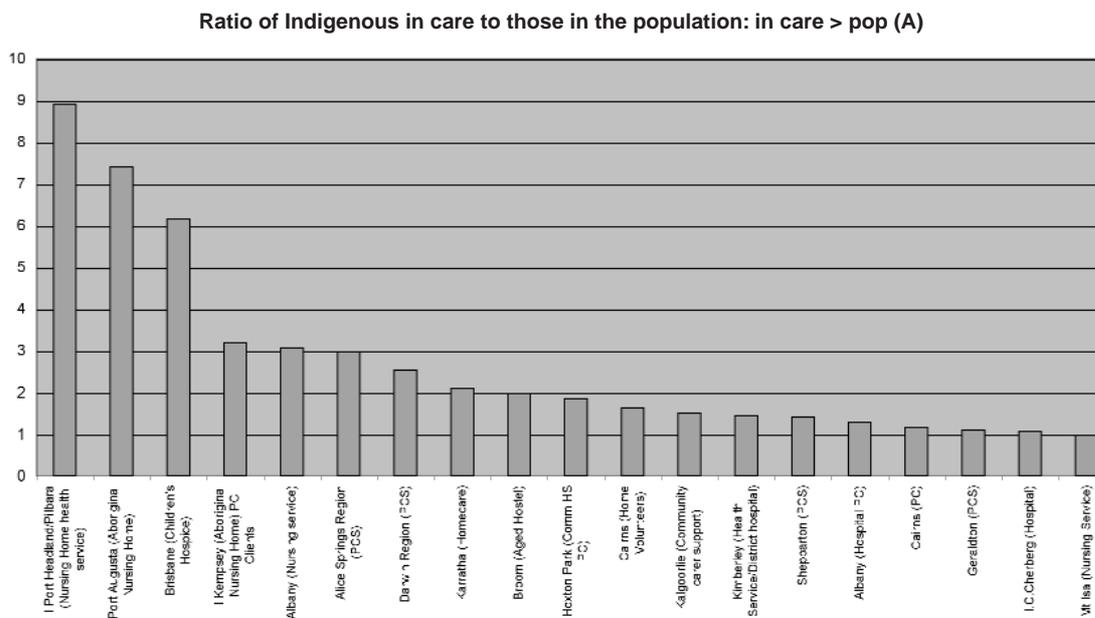
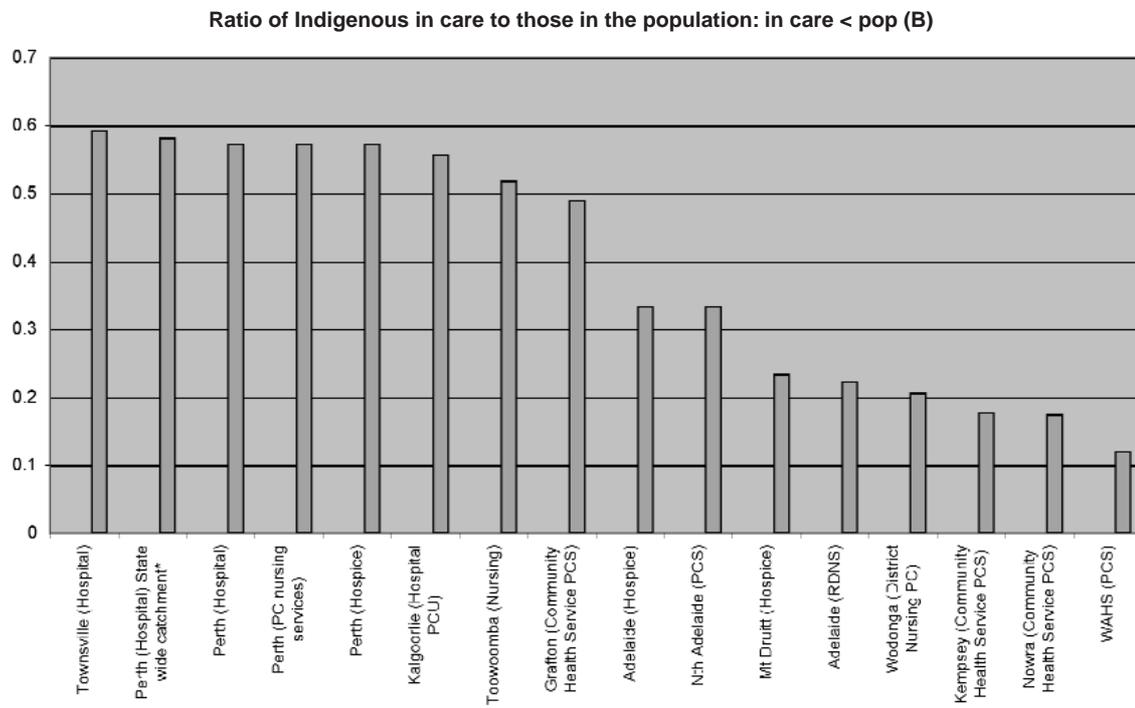


Chart B: shows the next 18 (ie numbers 20-37 on Chart 1)



Appendix 4



Bibliographies

- Main Indigenous Palliative Care Bibliography
- Training Resource Library
- Anthropological Library

Main Indigenous Palliative Care Bibliography

Palliative Caring at Home (SA), Palliative Care Council of South Australia.

This is a small and comprehensive booklet which explains palliative care and covers the practical issues involved in caring for the patient at home. The booklet includes contact numbers of a range of organisations in Adelaide that the carer may need to contact, including where to get equipment, counsellors, resources and more information.

Palliative Caring at Home (WA), Palliative Care WA, Silver Chain and the Cancer Foundation of Western Australia.

This is a small and comprehensive booklet which explains palliative care and covers the practical issues involved in caring for the patient at home. The booklet includes contact numbers of a range of organisations in for Western Australia, including health regions outside of Perth. This is a very practical and useful booklet which would be helpful to Indigenous people anywhere in Australia.

Understanding Morphine, by Mount Isa District Palliative Care Service.

Understanding Morphine was compiled by Mount Isa District Palliative Care Service to answer patients' and carers' questions about pain relief in plain language. It is beautifully illustrated by local Aboriginal artists Harry and Shannon Gertz, and is 'user-friendly' for Aboriginal patients and their families

(1978). 'World Health Organisation Alma Ata Declaration for Primary Health Care.'

(1989). *National Aboriginal Health Strategy*. Canberra, Australian Government Publishing Service.

(1993). Planning for Palliative Care in WA: Report of the State Planning Committee on Palliative Care, Health Department of Western Australia.

(1995). Palliative Care in Western Australia to the Year 2001, Part One, 'Metropolitan Area', Health Department of Western Australia.

(1996). *Palliative Care in Victoria: The Way Forward*. Melbourne, Vic Department of Human Services.

(1996). Palliative Care in Western Australia to the Year 2001, Part Two, 'Country Services', Health Department of Western Australia.

(1997). Palliative Care, The Plan for Western Australia, Health Department of Western Australia.

(1997). *Population Distributions, Indigenous Australians – ABS 1996 Census Data*. Canberra, Australian Bureau of Statistics.

(1999). The health and welfare of Australia's Aboriginal and Torres Strait Islander Peoples, Australian Bureau of Statistics.

(1999). *Multicultural Palliative Care Guidelines*, Palliative Care Australia.

Initiated by the Palliative Care Council of SA and Palliative Care Victoria, this is a guideline for health professionals and others working in, or associated with palliative care. It is not targeted to any specific culture, and includes Practice Guidelines (page 25) which are helpful in cross-cultural situations and which would be useful for professionals working with Indigenous peoples.

- (1999). New South Wales Aboriginal Health Strategic Plan 1999, State Health Publication No: (AH) 990151, NSW Health Department.
- (1999). *Standards for Palliative Care Provision*, Palliative Care Australia.
- (2000). Management of Diabetes Mellitus in Adults – Queensland Standard Care Pathway 2000, Developed by the General Practice Advisory Council (GPAC) in conjunction with the Queensland Health Outcomes Unit, the Brisbane Inner South Division of General Practice and the Queensland Allied Health Task Group and the Mater Centre for General Practice.
- (2000). National Palliative Care Strategy: A National Framework for Palliative Care Service Development, Commonwealth Department of Health and Aged Care.
- (2001). Better Health Care – Studies in the successful delivery of primary health care services for Aboriginal and Torres Strait Islander Australians, Department of Health and Aged Care: 1-104.
- (2002). *Palliative Care Service Provision in Australia: A Planning Guide*. (PCA). Palliative Care Australia.
- Adams, E. and Y. Schweizer (2001). Palliative Care in Queensland – Issues and Initiatives, Palliative Care Queensland. Volume 1: 1-123.
- Adams, E. and Y. Schweizer (2001). 'Palliative Care in Queensland – The State Defined.' Volume 2: 1-124.
- Armstrong, F. (2001). 'Australia needs more Indigenous nurses.' *Australian Nursing Journal* 8 (9): 28-30.
- Bailie, R., F. Siciliano, *et al.* (2002). *Atlas of Health Related Infrastructure in Discrete Indigenous Communities*. Canberra, ATSIC.
- Bennett, E., L. Manderson, *et al.* (1995). 'Dialysis and Renal transplantation among Aboriginal and Torres Strait Islanders in North Queensland.' *Australian Journal of Public Health*. 19 (6): 610-615.
- Bourke, E. A., R. Mobbs, *et al.* (1998). Developing an Aboriginal Palliative Care Strategy for South Australia. Adelaide, Aboriginal Research Institute. University of South Australia. Adelaide.: 45.
- Boyd, C. and D. Prior (2001). 'Net Generation: Online Education in palliative care.' *Palliative Care Australia Newsletter* (Summer Edition 2001): 14.
- Briscoe, A. (2000). 'Indigenous men's health access strategy.' *Aboriginal Isl Health Work J* 24(1): 7-11.
- Campbell, D., D. Small, *et al.* (1999). Improving palliative care in a multicultural environment, A joint initiative of Hope Healthcare Limited and Northern Sydney Area Health Service (Funded by Com Dept Human Service and Health – Palliative Care Projects Grants: 131.
- Cass, A., A. G. Gillin, *et al.* (1999). 'End-stage renal disease in Aboriginals in New South Wales: a very different picture to the Northern Territory.' *Medical Journal of Australia* 171(8): 407-410.
- Collis-McAnespie, O., P. Dunn, *et al.* (1997). The terminally ill Koori: their care and their carers: a qualitative project of service access and provision as seen through the eyes of a sample of individuals with a terminal illness and their carers in sections of rural New South Wales, Australian Rural Health Research Institute, Charles Sturt University, Wagga Wagga, NSW: 64.
- The research project described in this document looks at the needs of terminally ill Aboriginal people, their carers and family, using interviews conducted in the Macquarie Area Health Service and the Upper Western Sector of the Far West Area Health Service. This research was a partnership between

the NSW Aboriginal Health Resource Co-operative, the Australian Rural Health Research Institute at Charles Sturt University and the Macquarie Area Health Service, and was conducted by the first Aboriginal Health Education Officer – Palliative Care in the Upper Western Sector of the Far West Area. Topics covered include: a profile of the Aboriginal research assistant; literature review; project catchment area; project design and process incorporating: definition of a terminally ill Koori; research design and methodology; training of research assistants; development of the interview schedule; ethical procedures; access to participants; informed consent; rights to privacy; profile of participants; and geographic region of interviews; findings and issues for consideration including: Aboriginal culture and terminal illness; access to and quality of services; carer burden; and grief and loss. Two case studies which illustrate the use of support services are presented. The outcome of and issues raised at the National Aboriginal Health Workers Conference held in Sydney, April 1997 are outlined.

Cooper, G., M. Horsell, *et al.* (2001). 2001 Report to Parliament on Palliative Care in South Australia, Department of Human Services SA: 1-27.

Cox, B. (1998). 'About finishing up at Papunya.' *CARPA Newsletter* (28): 15.

Discussion of the issues surrounding death and dying (finishing up) in a traditionally orientated community (Papunya) in Central Australia

Derschow, B. (2001). 'Palliative Care in an Indigenous Setting.' *Palliative Care News* Winter 2001, Exploring Indigenous Palliative Care (Winter Edition): 5.

The article describes palliative care of Top End Aboriginal people, communicating with clients and families, and assisting people who wish to die in their own country. Some common practices such as not speaking the deceased person's name, ceremonial activities and the way grief is shown by families are briefly described.

Devitt, J. and A. McMasters (1998a). *Living on Medicine; A cultural study of end-stage renal disease among Aboriginal people*. Alice Springs, IAD Press.

Devitt, J. and A. McMasters (1998b). *On the Machine: Aboriginal stories about kidney troubles*. Alice Springs, Jukurrpa Books.

Dunn, P. (2001). 'Terminal Illness and Aboriginal People' *Palliative Care News* (Winter 2001): 7-8.

The article is an overview of a study in the care and carers of Aboriginal people with terminal illness in regional NSW. The study, titled 'The Terminally Ill Koori: Their Care and Their Carers', by Collis-McAnespie *et al.*, 1997 was published by Australian Rural Health Research Institute, Charles Sturt University, PO Box 588, Wagga Wagga. The study identified five key issues: the Koori view of terminal illness; access to services; quality of services; carer burden and managing grief and loss. These issues are briefly discussed in this overview.

Eades, D. ((1988)). Eades D (1988) They don't speak an Aboriginal language , or do they? *Being Black: Aboriginal cultures in settles Australia*. K. I. Canberra, Aboriginal Studies Press: 97-115.

Eastwell, H. D. (1982). 'Voodoo death and the mechanism for dispatch of the dying in East Arnhem, Australia.' *American Anthropologist* 84: 5-18.

A similar psychosocial sequence surrounds cases of voodoo death and cases where dying is expedited. Pre-death obsequies and fatalism in the victim are common to both. The death mechanism in both is dehydration by confiscation of fluids. Intervention in two voodoo death sequences in East Arnhem, Australia, involved re-hydrating the victim. As medical services extend to remote aborigines, deaths

with prominent psychosocial components that resemble voodoo death become diagnosable as orthodox medical conditions. 1 Table, 3 Figures. HA

Eastwell, H. D. (1984). 'Death watch in East Arnhem, Australia.' *Am Anthropol* (86): 119-121.

Adds to an earlier paper arguing that Aborigines practice passive euthanasia on old and infirm by withdrawing fluids.

Eckermann, A., T. Dowd, *et al.* (1992). *Binan Goonj: Bridging Cultures in Aboriginal Health*. Armidale, University of New England Press.

Fenwick, C. (2001). *Pain Management Strategies for Health Professionals Caring for Central Australian Aboriginal People*, Commonwealth Department of Health and Aged Care.

This is a learning resource designed to provide culturally sensitive information to help health professionals provide excellent pain care for Aboriginal patients. Clare is a Registered Nurse and Nurse Educator who worked in management of acute pain at the Alice Springs Hospital for five years. The book explains different kinds of pain, and explores cultural differences that may cause health professionals to misunderstand the pain experienced by Aboriginal clients. There are helpful sections on different pain management drugs and traditional bush medicines, and the book also explores the idea of 'cultural safety'.

Fischer, J. B. K. T. (1997). *Development of palliative care services in a remote and rural area*. Rural and remote Australia: health for all by the year 2000. Conference papers 4th National Rural Health Conference, February 9-12 1997, Perth, Western Australia, National Rural Health Alliance.

This paper discusses the experience of developing palliative care services in the Kimberley region of Western Australia. Some reference is made to palliative care for Aboriginals, including the need to have stronger Aboriginal participation in palliative care teams.

Fisher, T. (1998). 'I couldn't understand them so I would just sit there': Urban Aboriginal people's experience of renal disease, Indigenous Health Program (University of Queensland), In collaboration with Brisbane North Aboriginal and Torres Strait Islander Aged Care.

Flick, B. (1991). *A dying industry - or a way forward? Models of rural and remote health service delivery*. Rural and remote health papers 1991-98, Deakin West, ACT: National Rural Health Alliance, 1998.

The author outlines problems in delivering health services in the remote communities of Cape York, an area of chronic ill health with mortality levels 3.3 times higher than the general Queensland population. She then describes the role and services of the Apunipima Cape York Health Council, which was established as a community-controlled organisation in 1994. It works with the 15 major communities on the Cape to ensure maximum community-control and involvement in decision-making, while at the same time working with various mainstream services to ensure that the best care possible is available to the people of the Cape by addressing the enormous disparities that exist between the Cape and the rest of Australian society.

Franklin, M.-A. and I. White (1991). The history and politics of Aboriginal health. *The Health of Aboriginal Australia*. J. Reid and P. Trompf. Marrickville, Sydney, Harcourt, Brace, Jovanovich Inc.

Freckleton, I. (1998). 'Autopsy law: multiculturalism working successfully.' *J Law Med* 6 (1): 5-9.

The duties of a coroner to ascertain the cause of death of persons who have died sometimes surprisingly and without obvious medical reasons, have the potential to come into conflict with the

wishes of family members as well as with cultural and religious practices. A partial, although not entirely satisfactory, resolution has been arrived at in recent Victorian, New South Wales and Western Australian cases.

Fried, O. (1998). 'Cross cultural issues in the care of the Terminally ill in Central Australia.' *Menzies School of Health Research Newsletter ISS (22)*: 1.

Fried, O. (1999). "Many ways of caring': The Central Australian Palliative Care Paintings Project." *Palliative Care News Spring 1999 (Spring 1999)*: p10.

Equitable access to quality palliative care relies on the provision of services that are relevant and acceptable to the client populations. The clientele in Central Australia comprises both Indigenous and non-Indigenous people. Currently the staff of the Central Australian Palliative Care Service are all non-Indigenous people and they work within a Western biomedical model of care. The Service aims to reach all potential clients in the region by developing its practice in a manner that recognises and responds to their diversity, including their individual history and their cultural and language background. This paper describes, within the context of the history of the local Service, a cross-cultural education and promotion project Many Ways of Caring: the Central Australia Palliative Care Aboriginal Paintings Project, initiated by the Service and developed in collaboration with local Aboriginal people.

Fried, O. (1999). 'Many ways of caring: reaching out to Aboriginal palliative care clients in Central Australia.' *Progress in Palliative Care 7 (3)*: 116-9.

Equitable access to quality palliative care relies on the provision of services that are relevant and acceptable to the client populations. The clientele¹ in Central Australia comprises both Indigenous and non-Indigenous people. Currently the staff of the Central Australian Palliative Care Service are all non-Indigenous people and they work within a Western biomedical model of care. The Service aims to reach all potential clients in the region by developing its practice in a manner that recognises and responds to their diversity, including their individual history and their cultural and language background. This paper describes, within the context of the history of the local Service, a cross-cultural education and promotion project Many Way of Caring: the Central Australia Palliative Care Aboriginal Paintings Project, initiated by the Service and developed in collaboration with local Aboriginal people.

Fried, O. (2000). Cross cultural issues in the medical management and nursing care of terminally ill Aboriginal people in Central Australia. *Menzies School of Health Research, Alice Springs and Faculty of Medicine, University of Sydney*: 279.

Fried, O. (2000). 'Providing palliative care for Aboriginal patients.' *Australian Family Physician 29 (11)*: 1035-1038.

BACKGROUND: Aboriginal people's need for palliative care services are not being adequately met. **DISCUSSION:** Mainstream services need to be provided in concert with Aboriginal service providers, including health care workers, interpreters, liaison workers and cultural brokers, and should be adapted to patient needs. Effective cross-cultural palliative practice requires practitioners to examine their own beliefs and values and learn about the lives of their patients. Additionally, they need to recognise and defer to the cultural knowledge and personal authority of family members and relevant others within the Aboriginal community. **OBJECTIVE:** In accordance with contemporary palliative care principles of facilitating patient and family centred and culturally appropriate care, this article proposes ways in which health care services can be made more accessible and helpful to terminally ill Aboriginal people.

- Gaffin, J. (1995). 'Opening doors... a project aimed at improving access to hospice and specialist palliative care services by members of the black and ethnic minority community.' *European Journal of Palliative Care* 2 (1): 6-7.
- Gallasch, P. A. *Volunteer Training Manual*, Murray Institute of TAFE.
- Gray, A., P. Trompf, *et al.* (1991). The decline and rise of Aboriginal families. *The Health of Aboriginal Australia*. J. Reid and P. Trompf. Marrickville, Sydney, Harcourt Brace Jovanovich.
- Gunaratnam, A. (1997). Culture is not enough – a critique of multiculturalism in palliative care. *Death Gender and Ethnicity*. D. H. Field, J. Small, N., Routledge, London and New York.
- Haig, N. (1993). 'The Gardia experience: implications for occupational therapists working with Australia's indigenous people in the Kimberley Region.' *Aust Occup Ther J* 40 (4): 157-8.
- Working with Australia's indigenous people as an occupational therapist requires an understanding of Aboriginal culture. Non- Aboriginal (gardia) therapists, in the Kimberley region of Western Australia, have been challenged to revise their use of conventional therapy to work effectively with their traditional Aboriginal clients. Some of the cultural aspects which impact on the therapists' work include language differences, explanations of illness and death, complex laws governing family relationships, and attitudes to ageing and disabilities.
- Harkins, J. (1994). *Bridging Two Worlds: Aboriginal English and Crosscultural Understanding*. St Lucia, University of Queensland Press.
- Harrison, J. (1987). *Old People – Their Situation and Needs.*, Pitjantatara Women's Council. Alice Springs.
- Harrison, J. (1991). *Issues Affecting Old People.*, Central Australian Advocacy Service, Alice Springs.
- Harrison, J. (1995). *Optimal Standards of Care for Frail Aged Aboriginal People*, Menzies School of Health Research, Alice Springs.
- Harrison, J. (1997). *Social Policy and Aged Aboriginal People. Ageing and Social Policy in Australia*. A. E. Borowski, S. Ozanne, E., Cambridge University Press.
- Harrison, J. and R. White (1994). *Talking with Old People*, Central Australian Advocacy Service, Alice Springs.
- Harrison, J. and R. White (1996). *Education Kit on Advocacy and Aboriginal Residents' Rights*, Central Australian Advocacy Service, Alice Springs.
- Humphry, K., T. Weeramanthri, *et al.* (2001). *Forgetting Compliance: Aboriginal Health and Medical Culture 2001*, xi, 122 pp., Darwin, Northern Territory University Press in association with Cooperative Research Centre for Aboriginal and Tropical Health.
- Hunter, E. (1993). 'Aboriginal mental health awareness: an overview. Part 7: death, loss, dying and grieving.' *Aboriginal Isl Health Work J* 17 (6): 21-27.
- The health worker in an Aboriginal community may be expected to participate in the drama of death, loss, dying and grieving. While there is no formula to guide the health worker the main requirement is respect for people and for life. The author gives examples which demonstrate that activities associated with death are probably the oldest known rituals, and among the most diverse. He notes that, within Aboriginal and Islander Australia, the attitudes, emotions and rituals associated with

death also vary considerably. Loss, dying and mourning are then discussed from a cultural perspective, and from the perspective of the special roles that health workers can play.

Jack, C. M., L. Penny, *et al.* (2001). 'Effective palliative care for minority ethnic groups: the role of a liaison worker.' *International Journal of Palliative Nursing* 1997 7 (8): 375-80.

As the issue of equality of access to health-care services becomes more important, there is increasing concern that specialist palliative care services in the UK are under-used by minority ethnic groups (Haroon-Iqbal *et al.*, 1995; Karim *et al.*, 2000). Research into the provision of such services for black and minority ethnic communities identified a number of factors that contribute to a perceived low take-up of services was recommended. This article presents the important elements relating to equal access to specialist palliative care and the provision of culturally sensitive services, and examines the role of the Macmillan Ethnic Minorities Liaison Officer in the Bradford community palliative care team.

Jellie, C. and J. Shaw (1999). Palliative care information development: progress report on the national minimum data set for palliative care. *Palliative care information development : progress report on the national minimum data set for palliative care*, Clare Jellie and Janis Shaw. Canberra, Australian Institute of Health and Welfare.

There is a an urgent need for the development of a national minimum data set for palliative care to provide descriptive information in relation to palliative care (NMDS - palliative care) and to underpin the reporting of performance indicators. The aims of this report are: to describe the palliative care service delivery environment and implications for the development of the NMDS-palliative care; to provide an assessment of existing data collections relating to palliative care; to describe performance indicator data requirements and data development processes; and to provide information on work undertaken to date in developing the NMDS-palliative care, and to make recommendations for the future development of palliative care data.

Johnston, E. (1991). Royal Commission into Aboriginal Deaths in Custody, National Report. Overview and Recommendations. Canberra, Australian Government Publishing Service.

Kelaher, M. (1998). Community perceptions of health, illness and care : identifying issues for indigenous communities. *Australian Women's Health: Innovations in Social Science and Community Research*: 41-61.

Kellehear, A. (2000). The Australian way of death: formative historical and social influences. *Death and dying in Australia*. A. Kellehear. South Melbourne, Vic, Oxford University Press: 1-13.

How the particular national mixture of symbols and experiences of death have come about in Australia is the subject of this chapter. The sociological and historical processes that underlie the discussions and stories contained in this book are examined. It is argued that there is a need to understand how national experiences of death have evolved by identifying the formative influences on the Australian way of death, dying and loss. The influences discussed are: race relations history; the various processes of secularisation; medicalisation; Americanisation; and gentrification.

Kirk, M., C. Mc Michael, *et al.* (2000). *Breast Cancer: Screening Diagnosis Treatment and Care for Aboriginal Women and Torres Strait Islander Women in Queensland*. Brisbane, Queensland Health.

Lickiss, J. N. (1975). 'Health problems of urban Aborigines: with special reference to the Aboriginal people of Sydney.' *Social Science and Medicine* v.9 (6): 313-318.

25% of Aboriginal Australians, whose total number is 120,000-140,0 now live in cities. They have definite health problems of their own: high childhood morbidity, depressed growth rates, childhood delinquency, alcohol related problems, and psychopathology. Stresses suffered include urbanism for which Aborigines are typically ill prepared, migration stress, culture-conflict stress, and value dissonance with both white and traditional Aboriginal culture. Migration stress is mitigated by migration to cities where kinship groups already live, however. These sources of difficulty make plain the need for MD's to consider social problems, in an interdisciplinary approach, rather than clinical problems alone.

Lowe, P. and J. Floyd (1998). *Bessie's Story – Palliative Care in Remote Communities*, North Western Regional Palliative Care committee, PO Box 2202, Broome WA 6725.

Bessie's story aims to raise awareness about palliative care options in remote communities. It has been designed as an educational resource for health professionals.

Maddocks, I. (1999). 'Palliative care on the margins.' *Progress in Palliative Care* 7(3): 107-8.

Magarry, A. (2000). 'Current issues in palliative care.' *Health Matters* (6): 6-7.

Maher, P. (1999). 'A Review of 'Traditional' Aboriginal Health Beliefs.' *Australian Journal of Rural Health* 7 (4): 229-236.

McGrath, C. L. (2000). 'Issues influencing the provision of palliative care services to remote Aboriginal communities in the Northern Territory.' *Australian Journal of Rural Health* 8 (1): 47-51.

Compassionate care of the dying and their families by multi disciplinary teams in many settings is now available to many Australians. However, hospice care is mainly confined to the Westernised world. This paper aims to identify some of the issues that influence the provision of palliative care to Aborigines in remote communities in the Northern Territory. The paucity of literary sources of information demonstrates the need for research to be carried out in this field.

McLennan, W. and R. Maddon (1999). *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples*. Canberra, Australian Bureau of Statistics.

McNamara, B., K. Martin, *et al.* (1997). 'Palliative care in a multicultural society: perceptions of health care professionals.' *Journal of Palliative Medicine* 11 (5): 359-67.

This study assesses the perceived competence of 191 Australian palliative care professionals in delivering cross-cultural care. The relationship between the perceived competence levels of professionals and their experience and training is examined. Strategies to improve cross-cultural palliative care, as suggested by palliative care providers, are also presented. Information about perceived competence and the kind of difficulties encountered in cross-cultural palliative care interactions form the basis of suggested guidelines for proposed education programmes. The results of this study suggest that specific education, rather than individual experience of cross-cultural interactions, which may not always be positive, is needed to improve the competence of palliative care professionals. Education, therefore, is the key to the provision of culturally appropriate care to patients and their families from all cultural backgrounds.

- Mitchell, D. (1996). 'Sickening Bodies: How Racism and Essentialism Feature in Aboriginal Women's Discourse about Health.' *Australian Journal of Anthropology* v.7 (3): 258-274.
- Draws on interview data from Australian Aboriginal women in Western Sydney to illustrate the ways in which racism, oppression, and alienation from the self and the body contribute to the high rates of mortality and disease among this population. It is asserted that a damaged self-concept and corporeal hyperawareness can result from illness, a racialised status quo, or from an interaction between the two; thus, the body is not divorced from social meanings. It is shown how the meaning and interpretation of illness are socially constructed, and expressed at the community level as a form of embodiment associated with unequal colonial relations. The body and illnesses reflect identity alienation and social relations, and a gulf exists between modern medicine's diagnosis and treatment of illness and that of the Aborigines. 34 References. Adapted from the source document
- Mobbs, R. (1991). In sickness and health: the socio-cultural context of Aboriginal well-being, illness and healing. *The Health of Aboriginal Australia*. J. Reid and P. Trompf. Marrickville, Sydney NSW:, Harcourt, Brace, Jovanovich. p291-325.
- This chapter focuses on the inter-relationship between Aboriginal people and the Anglo-Australian health care system. It discusses Aboriginal health and illness beliefs, traditional healing systems and the interactions between non-Aboriginal health practitioners and Aboriginal clients. Some of the data presented is based on the author's anthropological fieldwork conducted with an Aboriginal community in a mining town in a remote area of Australia.
- Mobbs, R. (1995). *Developing an Aboriginal model for palliative care: description of a research project in South Australia*. Aboriginal health: social and cultural transitions: proceedings of a conference at the Northern Territory University, Darwin, 29-30 September 1995, Darwin, NTU Press.
- In South Australia, anthropologically-informed primary health care research is currently being undertaken to establish Aboriginal issues, needs and priorities. This research-in-progress paper describes a project funded by the Australian Government as a National Palliative Project. One aim is to develop a consultative and culturally sensitive research strategy which uses a social scientific methodology adapted to the ethical and fieldwork boundaries set by indigenous peoples. The second aim is to assess the palliative needs of terminally ill Aboriginal people and their carers at three locations in South Australia. The work of the Southern Community Hospice Program is described to illustrate the development of palliative care for terminally ill Aboriginal people.
- Mobbs, R. (1996). Developing Palliative Care for Aboriginal Australians: A strategy. A National Palliative Care Project. Nganampa Health Council Regional Report, Nganampa Health Council Regional Report, funded by the Commonwealth Department of Health and Family Services: 32.
- Murphy, S. (1999). 'Rural and Remote Palliative Care – Palliative Care in the Top End.' *Palliative Care News* (Spring 99): 4-5.
- Murphy, S. (2001). 'Education in the Top End (Northern Territory).' *Palliative Care Australia Newsletter* (Summer Edition 2001): 13.
- NHMRC (1991). Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Research, National Health and Medical Research Council, Canb, ACT.
- O'Brien, B., I. Blue, *et al.* (1997). A palliative care service delivery model with application in rural and urban settings. Adelaide, University of South Australia.

PCA *National Directory of Palliative Care Research, 4th edition.*

There are over 130 research projects listed in this edition (formerly called *Central Registry of Palliative Care Research*) which includes research from 1997 onwards. The directory holds summary information only and contact details of researchers.

PCA (1998). *National Compendium of Palliative Care Projects*, Commonwealth Department of Health and Family Services (4068).

The compendium includes a brief summary and contact details for each project funded through the National Palliative Care Program. The aim of the compendium is to disseminate the results of research projects.

PCA (2000). *Australia's Future In Palliative Care Research: A Collaborative approach*, Palliative Care Australia.

Pickhaver, A., M and P. D. C. Currow (2001). 'Celebrating of years of Palliative Care Education at Flinders, South Australia.' *Palliative Care Australia Newsletter* (Summer Edition 2001): 15.

Preece, C. (1997). *Community Development Project Looking at Indigenous Perceptions of Kidney Transplants in the Cairns Area*. Unpublished Community Health Development Project Report, Indigenous Health Program, University of Queensland: Brisbane.

Prior, D. (1999). Culturally appropriate palliative care for Indigenous Australian people. *Palliative Care Nursing: a Guide to Practice*. S. O. C. Aranda, M. Melbourne, Vic, Ausmed Publications: 102-116.

The purpose of this book is to assist practising nurses, especially those providing palliative care in non specialist settings. Chapter on culturally appropriate palliative care for Indigenous Australian people by Deborah Prior

Prior, D. (1999). 'Palliative care in marginalised communities [Review].' *Progress in Palliative Care* 7 (3): 109-115.

Prior, D. (2001). 'Cultural Safety in Palliative Care Issues for Research and Practice.' *Palliative Care News Exploring Indigenous Palliative Care* (Winter 2001).

The 1996 census counted approximately 400,000 Indigenous people who made up approximately 2.1% of the total Australian population. Providing culturally safe palliative care requires recognition of cultural difference and understanding the significance of practices associated with death and dying. The article describes some barriers preventing Aboriginal people from accessing palliative care, including cultural differences and different communication styles.

Prior, D. (2003). 'Palliative Care and Sorry Business.' *Aboriginal and Islander Health Worker Journal* 27 (1): 7-9.

Prior, D. M. (1997). *Life-death-life: Aboriginal culture and palliative care*. An ethnographic study of an urban Aboriginal community. Adelaide, Flinders University of South Australia.

This thesis explored issues which must be considered for developing culturally appropriate palliative care services for Aboriginal people in urban communities. The aim of the study was to learn from Aboriginal people about these issues and therefore a descriptive ethnographic approach was used. The ethnographic methodology used for this study incorporated the theoretical perspective symbolic interactionism and was informed epistemologically by social constructionism. This methodology was chosen because of its suitability to Aboriginal cultural beliefs and because the research methods

enabled one to gain an emic view of an Aboriginal community. Data collection occurred over a total period of twelve months. The first nine months involved interviewing and observing staff from several Aboriginal health care centres, for the purpose of developing a relationship and gaining information which needed to be considered before progressing to more intensive fieldwork. A full-time period of fieldwork was undertaken at Waratah Nursing Centre [pseudonym], which is a residential care facility for elderly and sick Aboriginal people. The participants of this study were selected purposefully on the basis of their knowledge of Aboriginal culture and their experience with life threatening illness, either as a patient or health care staff. Data collection methods included interviews, observation, participation in the daily activities of the residents of Waratah and accessing additional sources of data from other staff and from other written documents. The Ethnograph computer program was used to manage and store the data and Spradley's (1979) Development Research Sequence model facilitated a systematic process of data analysis. Three cultural themes emerged as being relevant to the aim of this study. These were, i) Aboriginality, ii) the process of communication, and, iii) how people dealt with health problems. The theme of Aboriginality was constructed from several sub-themes that included spirituality, history and cultural identity. Communication included concepts of non-verbal expression, techniques such as the pace of conversation, use of eye contact and questioning. The theme of dealing with health problems, incorporated experience and perception of hospitals and individual ways of dealing with health and illness.

The major finding of this study was the incongruence of Anglo-Australian approaches to palliative care with Aboriginal peoples' aspiration for self-determination, their ways of communicating and their social organisation associated with caring for their sick. Another key finding was that the concept of terminal illness, which is integral to the definition of palliative care, conflicts with the Aboriginal view of life-death-life as a continuum. Recommendations for improving cultural appropriateness of palliative care include reviewing assessment procedures to give a more integrated holistic focus which reflects the Aboriginal view of body-land-spirit, and having a culture-centred approach to grief counselling which recognises the significance of ceremonies and rituals. Another recommendation from this study is to improve the cultural awareness of non-Aboriginal staff by increasing education about Aboriginal history and culture. This strategy is recommended as a means of encouraging a closer liaison between mainstream services and the Aboriginal community health care staff. It would also have the effect of increasing Aboriginal influence on the future development of palliative care services.

Ramanathan, S. and P. Dunn (1998). 'Terminal illness in rural Aboriginal communities.' *Aboriginal and Islander Health Worker Journal* 22 (5): 23-26.

This project aimed to improve the level of information available to health service providers and planners on the needs of terminally ill Aboriginal people and carer(s) and to improve the access to quality and appropriate palliative care and support services for terminally ill Aboriginal People and their carer(s). The difference in relation to customs about death and dying was raised by several palliative care patients and their carers who were interviewed as part of a qualitative study of palliative care service provision as seen through the eyes of those with a terminal illness and their carers in parts of rural New South Wales. This article reports on the study, discussing the team approach undertaken by The Gilmore Centre at Charles Sturt University in association with the Macquarie Area Health Service and the NSW Aboriginal Health Resource Cooperative. The study area, project design and process, the participants, the interview process and issues for consideration are outlined and the publication of a report to share the findings of the study is noted: The terminally ill Aboriginal: their care and their carers. The project design and issues considered are presented.

- Reid, J. (1978). 'Change in the indigenous medical system of an Aboriginal community.' *Aust Inst Aboriginal Stud Newsl* (9): 61-72.
Beliefs and practices of a tradition-oriented Aboriginal community as they relate to illness and healing, north-eastern Arnhem Land.
- Reid, J. (1979). 'A time to live, a time to grieve: patterns and processes of mourning among the Yolngu of Australia.' *Cult Med Psychiatry* v.3: 319-46.
- Reid, J. (1983). *Sorcerers and healing spirits: continuity and change in an Aboriginal medical system*. Canberra, Australian National University Press.
Yolngu medical theory – ideas about sickness and death are explained in context of the Aboriginal community at Yirrkala, NT.
- Reid, J. and D. Lupton (1991). Introduction. *The Health of Aboriginal Australia*. J. Reid and P. Trompf. Sydney, Harcourt Brace Jovanovich: 1-36.
- Reid, J. and N. Williams (1984). "'Voodoo Death' in Arnhem Land: whose reality?" *American Anthropologist* (86): 121-33.
Argues that 'voodoo death' may not exist in any Aboriginal communities and that proposed mechanisms are far from proven.
- Reid, J., L. Yunupingu, *et al.* (1978). 'Caring for the aged and dying in an Australian Aboriginal community.' *Australasian Nurses Journal* 7 (12): 22-26.
Caring for the aged and dying in an Australian Aboriginal community in NE Arnhem land.
- Reynolds, H. (1999). *Why weren't we told?: A personal search for the truth about our history*, Penguin Australia.
- Ring, I. and N. Brown (2002). 'Indigenous health: chronically inadequate responses to damning statistics.' *Medical Journal of Australia* 177 ((11)): 629-631.
- Rosas, M., T. Weeramanthri, *et al.* (1993). 'Talking with families about sorry business.' *Aboriginal Isl Health Work J* 17 (5): 6-7.
There are about 20 deaths in Katherine township each year. Each death causes much sadness and discussion on why it happened. The team talked to ten families and conclude that deaths are primarily spiritual and social events for aboriginal people. They also need to be thought of as health events. These are opportunities to share different types of knowledge and respect traditional explanations as well as western medical explanations. (non-author abstract)
- Rowland, C. (2001). 'Taking the hole out of Holistic Palliative Care Education – the development and accreditation of an Holistic Palliative Care short Course.' *Palliative Care Australia Newsletter* (Summer Edition 2001): 12.
- Sampson, L. (1996). To support the establishment of a co-ordinated 24 hour palliative care service in Central Australia, Cancer Council of the Northern Territory.

Sharp, N. (1993). *Stars of Tagai : the Torres Strait Islanders*. Canberra, Aboriginal Studies Press.

Constitution of and change in Torres Strait Islander identity; exchange and cosmology; contact history; mythology, culture heroes and law; Malo-Bomai, Kwoiam; Meriam religious and social life - seasonality, clan territoriality, kinship, life cycle; the powers of the Zogole and the idea of traditional life; coming of the London Missionary Society and the accommodation of Christianity; changing rites of death and renewal – millennial movements; colonial administration – education , Protection Acts and protectionism, social control; colonial economy – trochus, pearling, beche-de-mer (trepan); background and effects of the 1936 strike and World War Two; moves for sovereignty – the Murray Island case; includes life histories

Shiple, D. and A. Trindall (1995). 'Aboriginal community health in South West Sydney.' *Aboriginal and Islander Health Worker Journal* 19 (4): 16-17.

The authors talk about their roles in community development for Aboriginal people living in Western Sydney. Programs and projects described cover the following areas: older people, women's health, diabetes, mental illness, palliative care, and Koori youth.

Smith, M. (2000). Death, health policy, and palliative care. *Death and dying in Australia*. A. Kellehear. South Melbourne, Vic, Oxford University Press: 116-129.

Loss and grief in Australian society are considered in this chapter in terms of Aboriginal culture; history of early settlement; premature mortality; culturally appropriate counselling; the effect of World War I and World War II; the model for grief in Australia; the Legacy movement; migrants; response to natural disasters; self help groups; and the establishment of the National Association for Loss and Grief in 1977. Australian research in loss and grief is reviewed, highlighting the attachment model and the phenomenology of bereavement. Questions of grief are explored in order to suggest directions which are needed to go forward. These include: bereavement in adults; the child's conceptualisation of death; biological aspects of bereavement; the social construction of dying; life support and organ transplants; euthanasia; the cultures of death and grief; mass media; violent death; and grief counselling.

Swan, P. (1998). 'Grief and health: the Indigenous legacy.' *Grief Matters* v.1 (2): 9-11.

Contemporary losses in Aboriginal communities may often produce high risk bereavement with adverse outcomes. There may also be an increased vulnerability associated with past unresolved losses which may have trans-generational effects. Knowledge of, and sensitivity to, cultural practices to deal with death and grief are essential in providing a supportive framework for Aboriginal people. There is also a need for policy and programs to support Indigenous people in dealing with trauma and grief. Prevention of loss and research is also critical. (Journal abstract)

Swan, P. (1999). 'Grief and Health: The Indigenous legacy.' *Palliative Care News* (Spring 1999): 8-10.

Contemporary losses in Aboriginal communities may often produce high risk bereavement with adverse outcomes. There may also be an increased vulnerability associated with past unresolved losses which may have trans-generational effects. Knowledge of, and sensitivity to, cultural practices to deal with death and grief are essential in providing a supportive framework for Aboriginal people. There is also a need for policy and programs to support Indigenous people in dealing with trauma and grief. Prevention of loss and research is also critical. (Journal abstract)

- Taor, A. (2000). 'Sense and sensitivity [A new draft RACGP statement on Aboriginal health encourages GPs to develop an understanding of Aboriginal culture, history and health issues].' *Australian Doctor*: 31-32.
- Thompson, N. and J. Irvine (2001). *A Review of Cancer Among Aboriginal People in Western Australia, Number 3*, Cancer Foundation of Western Australia. Perth, Cancer Foundation of Western Australia.
- Trollor, J. (1997). 'A survey of carers in the North West Health District of New South Wales.' *Australian Social Work* 50 (1): 51-55.
- Trudgen, R. (2000). *Why Warriors Lies Down and Die. Towards an understanding of why the Aboriginal people of Arnhem Land face the greatest crisis in health and education since European contact*. Parap, Aboriginal Resources and Development Services Inc.
- University of South Australia. Aboriginal Research Institute. (1998). *Developing an Aboriginal palliative care strategy for South Australia*. [Underdale, S. Aust., Aboriginal Research Institute University of S. Aust.
- Vines, P. (2000). 'Objections to post-mortem examination: multiculturalism, psychology and legal decision-making.' *J Law Med* 7 (4): 422-33.
- The author examines some of the legal issues relating to treatment of the dead which arise because of the cultural differences amongst various groups including Indigenous peoples. The dominant culture in Australia is a protestant/secular culture which is relatively robust and tends to view the issues relating to dead bodies in psychological rather than religious or cultural terms. Thus, even when objections to legal rules relating to death are voiced in cultural terms, the legal system tends to deal with them as psychological in nature rather than investigating the nature of the cultural difference. (non-author abstract)
- Wagstaff, P. (1997). *Appropriate Care: The palliative care needs of Victorian Aboriginal people*, Draft Report for the Victorian Department of Human Services.
- Wake, D., K. Martin, *et al.* (1999). 'Yarlparu : on sorrow and grief. [Talking to the families of dying Aboriginal people].' *Australian Nursing Journal* 6 (9): 16-18.
- Wake *et al* argue that nurses must be aware of the different ways Aboriginal people grieve the loss of their loved ones by examining the traditional mourning practices of the central and northern Australian Aboriginal people.
- Wakerman, J. and P. Field (1998). 'Remote Area Health Service Delivery in Central Australia: Primary Health Care and Participatory Management.' *Australian Journal of Rural Health* v.6 (1): 27-31.
- Examines the effectiveness of a variety of initiatives and changes made in remote primary health care service delivery in central Australia. Programs discussed include the introduction of an Aboriginal cultural awareness program, inclusion of local communities in the process of staff selection, development of policies and protocol to support practice, and increased support of staff through visits from managers. The decentralization of management was deemed to have the greatest impact. Overall, however, sustainable change has been difficult to achieve. Potential new initiatives are identified and discussed. 9 References. Adapted from the source document
- Wanganen, R. 'Self Healing and Spiritual Reconnection.' *Aboriginal and Islander Health Worker Journal* 18 (2).

Weeramanthri, T. (1995). 'Out of sadness, hope – a cause of death validation study and public health audit of adult Aboriginal deaths in the Northern Territory.' *Aboriginal Torres Strait Isl Health Inf Bull* (21): 73-76.

Weeramanthri, T. (1996). 'Knowledge, language and mortality: communicating health information in Aboriginal communities in the Northern Territory.' *Aust J Prim Health Interchange* 2 (2): 3-11.

Here the difficulties that non-Aboriginal health professionals experience in discussing health information with Aboriginal people in the Northern Territory are considered. Communication of information is seen as critical to the process of primary health care but beset by problems of language, different ways of 'knowing' and different values. Specific examples of communication difficulties are given from a five year research project that focused on the social and medical issues behind a series of adult Aboriginal deaths. The purpose of providing information at a community level is two-fold: first, to demystify an issue, process or structure and second, to get people talking. It is useful in communicative practice to view health information as having two equally important components: statistics and stories. All statistics are built up from individual stories, and effective information programs incorporate the story approach. Suggestions are made as to how primary health care practitioners can improve their communication practices. Before practitioners ask 'What do people need?' or 'What are their problems and how can they be addressed?', they need to ask first 'What do people know?' and second 'What do people value?'

Weeramanthri, T. (1996). 'Practice Guidelines for Health Professionals (Medical Practitioners, Nurse Practitioners and Aboriginal Health Workers) Dealing with the Death of a Northern Territory Aboriginal person.' *Menzies Occasional Papers* (1/96).

Weeramanthri, T. (1997). "Painting a Leonardo with Finger Paint': Medical Practitioners Communicating about Death with Aboriginal People." *Social Science and Medicine* v.45 (7): 1005-1015.

Australian medical practitioners' perceptions of the discrepancies between Western and Aboriginal beliefs of disease causation and death were investigated via interviews with 19 practitioners working in the Northern Territory, exploring how their perceptions influenced their reporting of mortality information to family members and their legal and practical obligations of reporting causation to coroners and requesting post mortem examinations. Practitioners expressed difficulty in maintaining respect for the Aboriginal culture due to Western legal and professional responsibilities. Also, discrepancies in the practitioners' and Aboriginal people's notion of blame caused problems. Although blame facilitates the restoration of social order in Aboriginal communities, it is concluded that Western conceptions of blame exoticise the Aborigines; consequently, Western medical systems should be perceived as cultural systems. 28 References. Adapted from the source document.

Weeramanthri, T., A. Parry, *et al.* 'Counselling Services Attached to Coroner's Offices across Australia.' *Aboriginal and Islander Health Worker Journal* 20 (1): 9-10.

Need for coronial counselling services and for improved coronial protocols relevant to Aboriginal families.

Weeramanthri, T., A. Parry, *et al.* (1995). 'Making connections, making sense: the land, body and spirit classification.' *Aboriginal Isl Health Work J* 19 (5): 23-5.

Why is this classification needed? We know that young adult Aboriginal people are dying of many kinds of medical diseases many years before they need to be dying. It is hard to identify and separate causes and links leading to such diseases since most medical diseases have underlying social causes.

- Weeramanthri, T. S. (1994). *Death and dying in Aboriginal communities: lessons for life*. Proceedings of the 1994 Northern Territory remote therapists' third workshop, Katherine, Northern Territory Dept of Health and Community Services.
- Williamson, P. (1996). 'Let me die in my country': Palliative care needs of Aboriginal people in the Kimberley and Pilbara regions of Western Australia, final report, July 1996. Broome, Australia. Dept. of Human Services and Health., Western Australia. Health Dept., National Palliative Care Project (Australia).
- Willis, J. (1999). Did he fall or was he pushed: Inquiring into Pitjantjatjara deaths. *Courting Death*. D. Manderson, Pluto Press: London.
- Willis, J. (1999). 'Dying in country: implications of culture in the delivery of palliative care in Indigenous Australian communities.' *Anthropology and Medicine* 6 (3): 423-435.
- In recent years, palliative care and hospice service providers have been criticised for their contribution to the increasing medical rationalisation of death and dying. At the same time, efforts to make palliative care more culturally appropriate for different ethnic minorities are criticised for their reification of cultural practices. Focus here is on three aspects of the process of dying for Pitjantjatjara Aborigines in central Australia – their preference for dying in their home 'country,' their wish to receive palliative care through matrilineal kin structures, and the difficulties of providing complex treatment in remote settings. The cultural and historical specificity of the Pitjantjatjara way of dying indicates that dying is a culturally mediated part of a specific way of living, the elements of which relate structurally to other aspects of the way of living. Because the underlying assumptions of palliative care models relate structurally to the cultures of dying in which they arose, one should not expect to be able to respond to cultural difference simply by changing details of service delivery. To provide culturally appropriate palliative care, it is necessary to ensure that the underlying assumptions of the care being provided relate to the culture of dying of the patients.
- Willis, J. M. (1995). 'Fatal attraction: do high technology treatments for end-stage renal disease benefit Aboriginal patients in Central Australia?' *Australian Journal of Public Health* 19 (6): 603-609.
- Wilson, T. (1998). 'Body rites : aspects of possession and control of the dead human body.' *Australian Property Law Bulletin* v.13 (no.5): 48-51.
- Woenne-Green, S. (1995). They might have to drag me like a bullock: the Tjilpi Pampa Tjutaku Project: the rights, needs and care options of the senior men and women of the Ngaanyatjarra, Pitjantjatjara and Yankunytjatjara communities in the cross-border region of Central Australia. Alice Springs, NT, Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council Aboriginal Corporation: 148.
- This project was funded and supported by the Users' Rights Section of the Aged and Community Care Division of the Commonwealth Department of Human Services and Health. The Tjilpi Pampa Tjutaku (all the old men's and women's) Project is an Aboriginal controlled project which arose from concerns of Women's Council members that senior men and women were too often being sent away to hospitals and nursing homes and too often dying away from their family and country. The aim of the project was to protect the rights of older people in the Aboriginal community and to ensure that there are services appropriate to their needs.

Training Resource Library

Palliative Care Resource Manual, Ngaanyatjarra Health Service.

This manual is designed for Clinic medical and Nursing staff. It explains what 'Palliative Care' is, Ngaanyatjarra Health Service's policy in relation to palliative care service delivery. Appendix 2 outlines some cultural considerations.

Understanding Morphine, Qld Cancer Fund and Qld Govt.

(1997). Over handover – a rural education initiative in palliative care nursing (video/transparencies). Bathurst, NSW, Produced by Iguana Films for Commonwealth Dept. of Human Services and Health, Mid Western Area Health Service NSW.

(2001). Grief and bereavement in palliative care – a video recording presented by Department of Health and Aged Care, Rural Health Education Foundation, Mawson, ACT.

Built around the work of Mr Mal McKissock, a grief counsellor operating the Bereavement Care Centre in Sydney. Dr Norman Swan interviews Mal McKissock about the techniques used in grief counselling.

Australian Rural Health Research Institute Contemporary Palliative Care Practices in Rural and Remote Australia: A Skills Development Package, National Palliative Care Program, Commonwealth Department of Health and Family Services.

Australian Rural Health Research Institute Development of a Rural Palliative Care Volunteer Education Training Package and Establishment of a Rural Community Palliative Care Volunteer Support Network, National Palliative Care Program, Commonwealth Department of Health and Family Services.

Boyd, C. and D. Prior (2001). 'Net Generation: Online Education in palliative care.' *Palliative Care Australia Newsletter* (Summer Edition 2001): 14.

Clarke, A., S. Andrews, *et al.* *Lookin' after our own – Supporting Aboriginal Families through the hospital experience.* Melbourne, Aboriginal Family Support Unit – Royal Children's Hospital, Melbourne.

Elsy, B. (1993). 'The development of a support network for palliative care workers in South Australian country areas.' *Australian Journal of Adult and Community Education* 33 (1): 64-65.

Freeman, M., S. Ramanathan, *et al.* (1998). 'Rural Palliative Care Volunteer Education and Support Program.' *Australian Journal of Rural Health* 6: 150-155.

Hefferan, J. M. (1997). Palliative Care in Rural and Remote Australia (and video), A collaborative project involving: The Australian Rural Health Research Institute, Iguana Films and JMH Media.

Lowe, P. and J. Floyd (1998). *Bessie's Story – Palliative Care in Remote Communities*, North Western Regional Palliative Care committee, PO Box 2202, Broome WA 6725.

Bessie's story aims to raise awareness about palliative care options in remote communities. It has been designed as an educational resource for health professionals.

McGowan, C. (1996). Sharing the Caring – Palliative Care for Rural Families (and video), Wodonga Institute of TAFE.

- Murphy, S. (2001). 'Education in the Top End (Northern Territory).' (Summer Edition 2001): 13.
- Pickhaver, A., M and P. D. C. Currow (2001). 'Celebrating of years of Palliative Care Education at Flinders, South Australia.' *Palliative Care Australia Newsletter* (Summer Edition 2001): 15.
- RCN Final Report of Palliative Care Distance Education Project 1999 and 2000, Royal College of Nursing, Australia.
- RCN Palliative Care Distance Education Project 2000: Final Evaluation Report, Royal College of Nursing, Australia.
- Rowland, C. (2001). 'Taking the hole out of Holistic Palliative Care Education – the development and accreditation of an Holistic Palliative Care short Course.' *Palliative Care Australia Newsletter* (Summer Edition 2001): 12.
- Weeramanthri, T. (1996). 'Practice Guidelines for Health Professionals (Medical Practitioners, Nurse Practitioners and Aboriginal Health Workers) Dealing with the Death of a Northern Territory Aboriginal person.' *Menzies Occasional Papers* (1/96).

Anthropological Library

- Akerman, K. (1969). Death and the significance of disposal methods and mortuary rites in Aboriginal Australia. Nedlands, University of Western Australia: iii, 60 l.
- Review of mortuary rites, modes of disposal of the dead, and mourning practices based on Australia-wide literary sources; individual, cultural and social aspects of death discussed
- Akerman, K. (1979). The Renaissance of Aboriginal Law In The Kimberleys. *Aborigines Of The West: Their Past And Their Present*. R. M. Berndt and C. H. Berndt, University of Western Australia Press: 169-183.
- Avery, J. (2002). 'Rights to mortuary rites.' *Indigenous Law Bulletin* 5 (14): 15-17.
- Bell, D. (1998). *Ngarindjeri Wurruwarrin : a world that is, was and will be*. North Melbourne, Spinifex Press.
- AN: Wide ranging contemporary ethnography of the Ngarrendjeri; introductory history of the author's involvement with the Ngarrendjeri and the Hindmarsh Island case; Ngarrendjeri sociality and identity – story possession, generational respect and knowledge, historical links to the past, crafts – basket weaving, feather working and use; cultural revival; mythological landscape – Ngurunderi and other creation heroes; stories and oral traditions linked to prehistory, historical context; Raukkan Mission and Christianity; life outside the mission; removal of children; Ngarrendjeri literature, language and music traditions – the Pata Winema song and singing; accounts of gatherings; problem of Ngarrendjeri religion; totemic (ngatji) relations and stories; kinship and relations to land; traditional territorial groupings; the miwi – feeling and wisdom; naming and the significance of genealogies; relationship to land – body metaphors and restricted places; initiation; burial places and practices related to the dead; signs and portents – mingka bird, willie wagtail, whales; sorcery and healing – dangerous spirits; politics of knowledge in the Hindmarsh Island dispute – argues for gender based knowledge in Ngarrendjeri society; discussion of the position of the dissident women; social conflict; problems of post-modern concepts of tradition – representation of the Ngarrendjeri in text; feminist anthropology in the region; women's knowledge and rites related to birth, the miwi, and

menstruation, Seven Sisters myths, cicatrisation, female initiation, depilation, infanticide; sex relations; race relations; women's business – problems of secrecy and the sacred; significance of Hindmarsh Island (Kumarangk) – trade, territorial grouping, mythology – Ngurunderi, Pleiades

Bendann, E. (1959). *Death customs : an analytical study of burial rites*. London, Kegan Paul.

Many references throughout to Australian Aborigines; causes of death, beliefs, mourning, life after death, totemic ceremonies, disposal of dead, name taboos

Berndt, R. M. (1942). 'Death, burial and associated ritual at Ooldea, South Australia.' *Oceania* v.12 (no.3): [189]-208.

Fieldwork at Ooldea Soak, 1939 and relevant information from A.G. Mathews of Ooldea; Antakirinja, Murunitja, Nangatadjara, Mandjindja and Wirangu tribes at Ooldea; Death, natural and magical preparation of corpse; burial – detailed examples of description of burial rites by informants at Ooldea – infanticide, reburial ceremonies; Economic aspect of burial; Role of widow or widower, mourning; Inquest, revenge and position of murderer; Beliefs concerning deceased's spirit; Part played by medicine men

Berndt, R. M. and C. H. Berndt (1962). Aborigines : disposal of the dead. *Australian Encyclopaedia*. 1: 70-75.

Deaths attributed to magic power; mourning, after death beliefs; Disposal of the body – N. and E. Qld., Darling and Murray R., lower Murray R., Ooldea, N.E. and N. central Arnhem Land mortuary ceremony, grave posts; Grave mounds in S.E. Aust., rites on Melville and Bathurst Is., removal of hand of dead person by Kurnai; Mourning chants (in English) from Arnhem Land and Melville Is.; Inquest and revenge Great Victoria Desert, western Arnhem Land, lower R. Murray, N. Qld., Darling-Murray R. Delayed inquest Forrest R., revenge expeditions, Central Aust., peace-making ceremonies, Arnhem Land; Life after death – Ooldea, Lake Eyre (Dieri), Arnhem Land, Cape York

Berndt, R. M. and C. H. Berndt (1988). Death and the Afterlife. *The World of the First Australians: Aboriginal Traditional Life: Past and Present*. R. M. Berndt and C. H. Berndt. Canberra, Aboriginal Studies Press.

Berndt, R. M., C. H. Berndt, *et al.* (1993). *A world that was : the Yaraldi of the Murray River and the Lakes, South Australia*. Carlton, Melbourne University Press at the Miegunyah Press.

Extensive and detailed ethnography of the Yaraldi (a dialect unit of the Kukabrak/Narrinyeri); physical environment; economic geography; population and disease; social composition, territorial organisation and their neighbours; kinship, clan structure and hierarchy; marriage, polygamy and the status of women – sexual relations, illegitimacy, elopement; genealogies of Albert Karloan and Pinkie Mack; maps of Brinkley Reserve and Murray Bridge; avoidance relationships; clan council; use comedy an examples of humour; trials of sorcery; subsistence economy; seasonality and division of time; hunting, fishing and gathering techniques; implements and equipment – canoes, spears, spear throwers, clubs, boomerangs, shields, traps and snares, nets, baskets, mats; food preparation; food preservation; cloak and rug making; extraction of animal oils; trade and exchange items; exchange relationships – the Ngengampi; food taboos; conception beliefs, spirit child and soul, pregnancy prevention, infanticide, childbirth; socialization – infancy and childhood, naming; sexual relations in childhood, puberty rites – cicatrisation, beliefs about menstruation, defloration; male initiation (associated games and ritual); marriage, elopement and other sexual relations; love magic; healing magic – familiars; the spirit world – the dead and other nature spirits; ceremonies, song types and their composition; mythic deities, culture heroes – Ngurnderi, Waiyungari and the wives of Nepeli;

other mythic beings – moon woman, birds (crow, crane, jay, magpie, pelican, native companion, emu), animals (water rat, whale, possum), amphibians, water, snake, fire; significance of the miwi and its use; reasons for, protection against, materials, methods and forms of sorcery; death and mortuary rituals; causes of death; summary of pre-contact culture and post-contact change; includes appendices 1) Kukabrak neighbours and dialectal units; 2) Kukabrak clans; 3) clan lands; 4) texts and translations; 5) genealogical tables; 6) traditional foods; 7) songs and translations

Bohemia, J. and W. B. McGregor (1991). 'Death practices in the north west of Australia.' *Aboriginal History* 15 (1-2): 86-106.

Bramell, E. (1935). '[Review of] Death and deferred mourning ceremonies in the Forrest River tribes / by Phyllis M. Kaberry.' *Mankind* v.1 (no.12): 22.

Brandl, M. (1980). *Wuluguman and Wulman. Notes on the aged in Aboriginal society.* Canberra, Centre for Resource and Environmental Studies, Australian National University: 28.

Bulmer, J. (1994). *Victorian Aborigines: John Bulmer's recollections 1855-1908.* Melbourne, Museum of Victoria.

Compilation and annotations of the works of missionary John Bulmer. Bulmer's writings on Victorian Aborigines from Yelta, the Wimmera, and Lake Tyers; life and culture of Aboriginal people living at Lake Tyers mission in the late 1800's; childhood and adolescence – socialisation, play; marriage and kinship – class system, mother-in-law avoidance; leadership; beliefs in the supernatural; social control – leadership, punishment and conflict; death, mourning and burial practises; religion and mythology; 'How the Aborigines became black', 'The origins of fire', 'The flood', other creation and cautionary myths; Nargan or the Bunyip; games, corroborees and songs; hunting and fishing; food and its preparation; canoes, nets, spears, ground-edge axes and rugs; attacks on Aboriginal people by settlers ; word list

Cane, S. (2000). *Pila Nguru : an ethnography of the Spinifex People in the context of native title:* 182 leaves.

Land claim report for Ngalea/Wangkayi/Pitjantjatjara 'Spinifex people' occupying the eastern Great Victoria Desert region; tribal and language identifications; claimant identification – genealogies and family trees; modes of affiliation and ownership of land – includes detailed illustration of individual affiliations ; associations with major Dreaming tracks; concept of land ownership; archaeological and historical evidence; subsistence and settlement patterns; contact history – includes accounts of early contacts – Cundeelee, Coonana, Yakatunya, Tjuntjuntjara; mission and patrols; major myths and mythological entities – Bush Turkey, Zebra Finch, Evil Spirits (mamu), Two Men, Seven Sisters, Python, Eagle, Woman and Sons, Thorny Devil, Kangaroo, Native Cat, Water Snake, Emu, Feral Cat, Dingo, Old man, Magpie, Frog; contemporary social life – possessions and uses of western material culture (Toyota, houses, cloths), money (value and use, shopping, symbolic value of money in the ritual economy, gambling); social life – age division (dealing with the external world), ceremonial activity, social control and punishment, protocols for visiting; child rearing and life cycle – discipline, education, initiation, marriage, death; leadership – group status; settlement structure – Tjuntjuntjara; forms of traditional rights; Appendix, 1 – Site maps; 2 – Family Trees (genealogies); 3 – Bush Names; 4 – History Data Base

Cawte, J. (1975). 'Australian Aboriginal medicine before European contact.' *Annals of Internal Medicine* v.82 (no.3): 422-423.

Brief description of treatment for snake bite, pneumonia, general debility in northeast Arnhem Land; healer-patient relationship compared with western society; Aboriginal medicine as a form of law (example; malgri disease of Mornington Island Lardil tribe); Mourning practices briefly described; Mentions Kaiadilt of Bentinck Island

Clark, S. J. and S. D. Hillman (2001). Information and support pack for those bereaved by suicide or other sudden death, Ministerial Council for Suicide Prevention, TVW Telethon Institute for Child Health Research. 2001.

Clunies-Ross, M. (1989). 'The aesthetics and politics of Arnhem Land ritual'. *TDR Winter*: 107-127.

Crawford, F., P. Dudgeon, *et al.* (2000). Interacting with Aboriginal Communities. *Working with Indigenous Australians: a handbook for psychologists*. p. Dudgeon, P. Garvey and H. Pickett. Perth, Gunada Press: 185-201.

Davidson, D. S. (1948). 'Disposal of the dead in Western Australia'. *American Philosophical Society – Proceedings* v.93 (no.1): 71-97.

Based on previously published reports and author's field-work in 1930-1931 and 1938-1939; Considers distribution of various types of burial, cannibalism, mourning for W.A. and adjoining areas

Douset, L. (1997). 'Naming and personal names of Ngaatjatjara-speaking people, Western Desert: some questions related to research.' *Australian Aboriginal Studies* 2: 50-54.

Dussart, F. (1990). *The choice of widowhood among Warlpiri women*. Sixth International Conference on Hunting and Gathering Societies, CHAGS 6; hunting and gathering societies changing peoples, changing theories, University of Alaska Fairbanks – Alaska, University of Alaska Fairbanks.

Status and options of widows in Warlpiri society; traditional marriage and mourning patterns compared with more contemporary practice where more women remain single; greater economic independence allows widows to adjust alliances on more personal criteria; kin and peer pressure to re-marry; courtship among widows

Eastwell, H. (1982). 'Voodoo death and the mechanism for dispatch of the dying in East Arnhem, Australia.' *American Anthropologist* 84 (March): 5-18.

Eliade, M. (1968). Death, eschatology and some conclusions. *History of Religions*. v.7: 244- 268.

Death, funerary rites and inquest; the role of medicine men; mourning and other manifestations of grief (Murngin, Arnhem Land); identification of murderer, forms of inquest; Post-existence of the soul – beliefs from Arnhem Land, Wiradjuri, Kulin, Kamilaroi, Gunwinggu tribes, E. Kimberley, Herbert R.; Notes on the Kurangara cult in Kimberleys (Wunambal, Ungarinyin), sacred object of cult; the Djamba cult and its relation to Kurangara; Wandering cults and millenaristic movements; Religious ideology replaced by magic; New cult of Jinimin (Jesus), relative myths (Canning Desert region); Adjustment movement in Elcho Island; Historical reconstruction of Australian cultures; megalithic cultures integrated into religious life of Kimberley and Cape York tribes; Analysis of religious culture

Ellis, R. W. (1975). 'The funeral practices and beliefs of the Adnjamathanha.' *Anthropological Society of South Australia* v.13 (no.6): 3-10.

Detailed account of Flinders Ranges, disposal, mourning (inc. moiety differences), orientation of body, inquest methods, after death beliefs; gives English versions of myth on origin of human mortality and myth on first burial; describes methods of ritual killing (boning, cylcons, etc.), ritual cannibalism

Fawcett, J. W. (1897). 'A burial ceremony of the Waw-wyper tribe'. *Australasian Anthropological Journal* (no.6): 125.

Manning River district; method of burial, and mourning

Fraser, J. F. (1962). 'The Aborigines of New South Wales.' *Royal Society of NSW* v.16: 193-233.

Theory of origin; Study of the Gringai, Kamilaroi, Ocalaroi and briefly, the Wiradjerry and Yuin tribes; Notes on birth, infanticide, care of children, education – scarification, hunting kangaroo, fishing (Brewarinna fish traps and spearing), axe-sharpening near Yaggabi on the Gwydir; Initiation, description of Gringai Bora, meanings of the bora ground circles, body painting, use of bull-roarer; Laws of descent relationships, condition and duties as a man, laws and government, punishment for offences tribal fight described, healing by the Koradjiie or medicine-man; black magic; Old age – treatment of elderly people, burial, mourning, sky legends

Fry, H. K. (1949). 'A Bathurst Island mourning rite.' *Mankind* v.4 (no.2): 79-80.

Native camp about 2 miles from Point Brace; Names of dead, taboo; Magic connected with burial; Census of Island

Glass, A. and R. Robinson (1990). *Into another world : a glimpse of the culture of the Ngaanyatjarra people*. Alice Springs, Institute for Aboriginal Development.

Description of geographical and historical background of Ngaanyatjarra settlement at Warburton; phonology and wordlist; etiquette; kinship and marriage; birth and childhood; initiation; death; problems of change

Goodale, J. C. (1959). 'The Tiwi dance for the dead.' *Expedition* v.2 (no.1): 3-13.

National Geographical Society expedition, Melville Island, 1954, on which author recorded 4 separate funeral ceremonies; Full description of burial poles, implements and colours used; Mourning rites; Painting of body and face to obliterate features for ceremonies; Songs which are sung are composed by the singer

Gould, R. A. (1970). 'Journey to Pulykara.' *Natural History* v.79 (no.10): 56-57.

Based on field work in 1969 at Pulykara (Gibson Desert); notes firing of ground for hunting, describes environment and camp, native well (Ngatjara people), ritual mourning, plant foods, division of labour, plant names, game hunting methods (use of blinds), dingoes, stone tools, care of old people, kinship; obligations; table shows comparisons of vegetable staples 1966-67 and 1969-70

Greenway, J. (1962). *Peoples and cultures of Australia*. Boulder, University of Colorado.

Correspondence study, including 27 assignments, and complete list of tribes and their locations (Tindale); Table of physical characteristics; Notes on prehistory, diseases, archaeology, implements and artefacts, types of food, trading habits, clothes and ornaments, marriage and kinship relationships, tribal organisation, initiation (circumcision, ceremonies), religion, totemism, magic, death;

(mourning, burial), mythology, music (songs), art, language and list of linguistic groups, early contacts and conflicts, present contacts

Gunther, J. (1837). A Wiradjuri burial, 1837: [6] leaves.

Wiradjuri burial ceremony; mortuary; death; mourning

Haddon, A. C. (1904). Funeral ceremonies. *Cambridge Anthropological Expedition*. Reports. v.5: 248-262.

Customs – Mabuiaig – skull giving ceremony, death dance; notes on customs on Tutu, Muralug; mourning

Place: Mabuiaig / Jervis Island (Qld TSI SC54-07) Language/Group: Torres Strait Islanders (Qld TSI SC54, SC55)

Hart, C. W. M. and A. R. Pilling (1960). *The Tiwi of North Australia*. New York, Holt.

Theory of origin of Australian Aborigines; Tiwi marriage, daily life, joint activities; Prestige and influence, acculturation; Status of women; warfare; death and mourning ceremonies; initiation; History of Missions Bathurst and Melville Islands, change from patriliney to matriliney

Hart, C. W. M. and A. R. Pilling (1962). *The Tiwi of Northern Australia*. New York, Holt, Rinehart and Winston.

Hausfeld, R. G. (1960). Aspects of Aboriginal station management, Sydney University: 100p.

Study undertaken at Woodenbong Station, 1956-1960; p.1-7; Introduction, location, definitions; p.8-15; Section 1, History of settlement of upper reaches of Richmond and Clarence Rs p.16-22; Section 2, Language – Githebul dialect of Bandjalang, fluency, attitudes to use of language, corruption, use of English, lack of literacy; p.23-32; Section 3, Population origin of station population, population movement, age and sex groupings, caste; Aboriginal ancestry, racial origin of population, population forecast; p.32-39; Section 4, The land and the people, tribal lands, land rights of Bandjalang tribe, inheritance, clan countries of Gullyvul, Wurlavul, Githebul, Yugurabul and Yukumbear clans, affiliations of residents; p.40-45; Section 5, Material culture, food, nutrition, housing, transportation, dress, real and personal property, standards of value and exchange, inheritance; p.55-60; Section 6, Employment, types available, degrees of skill, wages, treatment of and by employers; p.61-65; Section 7, Art and recreation, music, sport, card games; p.66-67; Section 8, The family, marriage and sex, traditional marriage customs, analysis of present marriages to show changes, family ties, kinship and avoidance relationships, control of children, sexual relations; p.78-82; Section 9, Kinship, links with other settlements at Guyra, Moree, Cherbourg and Taree; p.83-87; Section 10, Social groups and social control, clan groups, age and sex groups; p.88-90; Section 11, Totemism; p.91-93; Section 12, Mythology, spirit beliefs; p.94-98; Section 13, Secret life, clever men, magic; p.99-105; Section 14, Religion, Station Church, Pentecostalism, relationship between traditional beliefs and Christianity; p.106-108; Section 15, Death and burial rituals, orientation, mourning; p.109-116; Section [16], Attitudes, to Europeans, Station Manager, Aborigines Welfare Board, police, education; p.117-124; Section 17, Education, primary, secondary, attainments, adult education; p.125-146; Section 18, Administration, law, regulations, discipline, health and hygiene, management; p.147-151; Section 19, Assimilation; p.156-159; Section 20, The future, maintenance of group identity, solutions for housing and employment problems; Appendix I, Notes and reference for text; Appendix II, Brief details of informants; Appendix III, Sample genealogical table; Appendix IV, Additional material (genealogies, totemic sites); Appendix V, Photographs – cicatrization, shelter, physical appearance of part-Aborigines; Map shows Bandjalang tribal country

Healthy Aboriginal Life Team (1991). *Anangu way : Iriti pukulpa pika wiya nyinantja munu pukulpa pika wiya kunpu nyinantjaku ngula = In the past we were happy and free from sickness : and in the future we will become strong and healthy again [Pitjantjatjara/English]*. Alice Springs, N.T. Nganampa Health Council.

Anangu concepts of health and related issues; paintings and stories stating the concerns of Anangu for diet, misuse of alcohol, petrol sniffing, food gathering and hunting patterns; categories of food; celebrations of life; grieving for death; regeneration of life and kinship with the land; Yankuytjatjara; Pitjantjatjara; Ngaanyatjarra

Howitt, A. W. (1986). 'Burial practices of the native tribes of south east Australia.' In: *Religion in Aboriginal Australia: An Anthology*: 221-240.

Hunter, E. M. (1993). 'Aboriginal Mental Health Awareness : an overview part seven. Death, loss, dying and grieving.' *Aboriginal and Islander Health Worker Journal* v. 17 (no. 6): 21-27.

General discussion of attitudes to death and loss including death and mourning; some brief reference to Aboriginal responses

Jacob, T. (1991). *In the Beginning: A Perspective on Traditional Aboriginal Societies*, Ministry of Education, Western Australia.

Kaberry, P. M. (1935). '[Review of] Death and deferred mourning ceremonies in the Forrest River Tribes...' *Oceania* v.6: 33-47.

Death – Mourning

Forrest River (WA East Kimberley SD52-09, SD52-10,SD52-14)

Keen, I., Ed. (1988). *Being Black: Aboriginal cultures in 'settled' Australia*. Canberra, Aboriginal Studies Press.

Langton, M. (1990). Too much sorry business – The Report of the Aboriginal Issues Unit of the Northern Territory. *Royal Commission into Aboriginal Deaths in Custody: Final Report*. E. Johnston. Adelaide, Australian Government Publishing Service. 5.

Lommel, A. and D. Mowaljarlai (1994). 'Shamanism in North-western Australia.' *Oceania* 64 (4): 277-287.

Lui, A. L. (1988). The last farewell : maintaining customary practice in Torres Strait Islander society. Townsville, James Cook University of North Queensland: vi, 106 leaves.

Analysis of the contemporary tombstone opening ceremony; links with pre-contact mourning ceremonies; effects of Christianity on ritual; original fieldwork in 1987, based on ceremonies held in Townsville and Cairns

MacDougall, J. (1980). *The House Opening*. Canberra, AIAS.

When Geraldine Kawangka's husband died she and her children left their house at Aurukun on Cape York Peninsular. In earlier times, a bark house would have been burnt, but today a 'house-opening' ceremony – creatively mingling Aboriginal, Torres Strait and European elements – has evolved to deal with death in the midst of new living patterns. This film records the opening of the house and Geraldine's feelings about it in her informative and personal commentary.

- Maddock, K. (1974). *The Fall into Death. The Australian Aborigines: A Portrait of their Society*. K. Maddock. Ringwood, Penguin.
- Maddock, K. and J. E. Cawte (1970). 'Aboriginal law and medicine.' *Proc Med Leg Soc New South Wales* (4): 170-92.
Discusses several branches of Aboriginal law, in particular, reaction to death; also discusses the relationship between traditional medicine and law, concluding the medicine is weak on technology and disease but strong on family orientation, influencing behaviour and forestalling conflicts.
- Marett, A. (2000). 'Ghostly Voices: some observations on song-creation, ceremony and being in NW Australia.' *Oceania* 71 (1): 18-29.
- Martin, D. F. (1984). *Saddles without horses : Aboriginal adaptation to white Australia*. London, University of London.
Wik Mungkan response to culture change at Aurukun; traditional territoriality; myth, ritual and totemism; men's/women's economic roles; kinship/marriage; language and social identity; current social dynamics, Shire Council and availability of government funds; new territorial symbols and access to new resources; strategy and grief on death; inclusion of cash in economy, social service benefits, gambling
- McConnel, U. (1937). 'Mourning ritual among the tribes of Cape York Peninsula.' *Oceania* v.7 (no.3): [346]-371.
Refers principally to the Wik-Mungkan and adjoining tribes; Deals with ritual consumption of flesh of dead relatives, disposal of dead in caves, by interment, preservation by desiccation, mourning rituals, cremation, beliefs concerning death and the after life; Phonetic texts of myths relating to death, with literal translations
- McGrath, C. L. (2000). 'Issues affecting the provision of palliative care services to remote Aboriginal communities in the Northern Territory.' *Australian Journal of Rural Health* 8 (1): 47-51.
- Meggitt, M. J. (1962). *Desert people: a study of the Walbiri Aborigines of Central Australia*. Sydney, Angus and Robertson.
Ethnography of the Walbiri (Waljbiri); physical environment, includes table of Walbiri flora, with language and Latin names, uses; history from 1862, contacts with Australian explorers, pastoral settlement, violent conflict, establishment of Aboriginal settlements; contemporary distribution, numbers, relations with neighbouring groups, ethnocentrism; local organisation, sections, subsections, personal mobility in relation to religious significance of country; kinship system, residential family unit, marital relations, discord, elopements, adultery; socialisation, relations between parents and children, other kinfolk; moieties, descent; progressions through age-grades; law, social control; betrothal, marriage, childbirth; initiation, circumcision, subincision; death, funerary practices, child vs adult, man vs woman, causes of death, mourning
- Morphy, H. (1984). *Journey to the crocodiles nest: an accompanying monograph to the film, Madarrpa funeral at Gurkawuy : with an afterword by Ian Dunlop*. Canberra, Australian Institute of Aboriginal Studies.
Interpretive account of child's funeral at Gurkawuy outstation, Trial Bay; Yolngu social organisation (particularly clan formation and marriage); contact history; outline of religious beliefs including relationship to ancestors, land, law role of songs, dances and painting; attitudes to death and

mourning; concept of souls; mortuary practices (including change); names of participants; detailed account of the ceremony; meaning of ritual episodes; sociological analysis of relationships between participants; choice and decision in ceremony construction; Afterword by Ian Dunlop separately annotated

Mowaljarlai, D. and J. Malnic (1993). *Yorro yorro: Everything standing up alive: spirit of the Kimberley* Broome, W.A., Magabala Books.

Account of journeys with David Mowaljarlai to significant sites in the west Kimberley; includes associated mythology and religious knowledge – Wandjina, snake, celestial bodies, sun, weather, lightning, flood, clouds, insects, birds, kangaroo, sickness, culture heroes; stone arrangements; food preparation – kangaroo; mother-in-law relations; foundation of the law; creation beliefs and cosmology; origin of spirit children and conception; magical and healing powers of the banman (doctor/clever man) – cure of leprosy; after death beliefs and mortuary ritual; incorporation of Christianity; autobiography of David Mowaljarlai – life on Kunmunya mission, recollections of J.R.B. Love, World War II; forms of dreams – Mowaljarlais visions – corpus Australis; world view; Appendix 1 – Features of a Wandjina; Appendix 2 – Waanangga, sugarbag; Appendix 3 – time periods – chronology; Appendix 4 – The body of Australia, corpus Australis; glossary of Aboriginal language

Myers, C. S. and A. C. Haddon (1908). Funeral ceremonies. *Cambridge Anthropological Expedition... Reports*. v.6: 126-162.

Keber ceremonies, singing, preparation for mummification; Body decoration at ceremonies; Funeral songs, mourning, (Murray Islands, Dauar)

Myers, F. R. (1988). 'From ethnography to metaphor: recent films from David and Judith MacDougall.' *Cultural anthropology* Vol. 3 (no. 2): [205]-220.

An appreciation of five films on various aspects of Aboriginal life set in Aurukun and New South Wales; topics include – the Queensland Government attempt to take over the management of the Aurukun Aboriginal Reserve, mourning ritual, stock work and station life, site recording (documentation by Peter Sutton) Personal subject: Sutton, Peter, 1946-

Myers, F. R. (1989). Burning the truck and holding the country: Pintupi forms of property and identity. *We are here; politics of Aboriginal land tenure*. E. N. Wilmsen. Berkeley, University of California Press: 15-42.

Concepts of ownership, property and identity in Pintupi society; possessions and exchange – food motor vehicles (Toyotas); relation to land and ownership of ritual objects – includes discussion of claims of association with place (Kintore) and the exchange of ritual objects; death and the dissolution and transmission of social identity – role of memory and mourning

O'Connor, M. C. (1994). 'Women's business (Aboriginal health).' *Australian Family Physician* v.23 (1): 40-41, 43-44.

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Appendix 5



Literature summaries

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e) Prior, D. (1999). 'Palliative care in marginalised communities [Review].' <i>Progress in Palliative Care</i> 7(3): 109-115. Prior, D. (2001). 'Cultural Safety in Palliative Care Issues for Research and Practice.' <i>Palliative Care News Exploring Indigenous Palliative Care</i> (Winter 2001).	289
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1.0 Summary and critique of four key reports and four articles

- a) Bourke, E A, Mobbs, R *et al.* (1998) Developing an Aboriginal Palliative Care Strategy for South Australia Aboriginal Research Institute. University of South Australia. Adelaide.

The report by Bourke, Mobbs, Engelhardt and Graham is the final report of an Australian Government funded investigation into the feasibility of an Aboriginal Palliative Care Strategy for South Australia. The research involved both quantitative and qualitative assessment of the needs of terminally ill Aboriginal people and carers. The project was funded in 1995 and also produced three regional reports relating to specific areas of field research. The project included agency and community consultations in Adelaide, Ceduna, Point Pearce, Port Vincent and Port Augusta areas. Field research was conducted on the Anangu Pitjantjatjara Lands, Yorke Peninsular and in Adelaide. Consultations held in Port Augusta are reflected throughout the report. Field research was based on community-owned qualitative data collection methods developed as a result of consultations with Aboriginal organisations.

The authors refer to the serious sensitivities involved in the development of appropriate methods for qualitative investigation of issues around indigenous death and dying, reporting that suspicion and scepticism towards the project were initial concerns, as was the need for flexibility in the approach to data collection between sites. This flexibility was reflected in concerns raised around health providers' assumptions that all indigenous communities have identical cultural concerns, a view which was emphatically questioned by those consulted.

The report provides a comprehensive overview of the data which are relevant to an understanding of indigenous death and dying, including morbidity and mortality rates, life expectancy, causes of death and frequency of evacuations from remote communities. Of particular interest are data relating to mortality rates of urban and non-urban indigenous people, which demonstrate the seriously higher mortality rates for indigenous people in country areas of South Australia. The report links quantitative data with the implications for indigenous people experiencing palliative care needs which are not matched by the provision of resources.

It contrasts non-indigenous concepts of palliation with the reality of provision of care which is currently occurring within indigenous communities but may not be labelled or understood as 'palliative care'. It recommends that a palliative care strategy build on and resource this practice, rather than impose potentially inappropriate or harmful initiatives. Aboriginal involvement in such developments is seen as critical.

Recommendations which relate to both the importance of education within indigenous communities around palliative care and the need for cross-cultural awareness training of non-indigenous health staff are emphasised.

The development of a palliative care strategy is seen to most appropriately occur within the context of broader planning and provision of health services in South Australia. The authors strongly recommend that provision of palliative care not be seen in isolation from the broader framework of indigenous health policy and Indigenous Health Agreements, both at regional and State level. This approach, they maintain, would ensure collaboration, access to and organisation of resources, and enhanced communication regarding best practice. It would also ensure indigenous control of palliative care related outcomes. The report recommends development of a State-wide Working Group of those involved with, or responsible for, indigenous health and palliative care delivery. The group would be established to make specific recommendations relating to services, education and program development.

Significant Issues Identified in the report include:

- Different regional areas require differing methodological approaches as there is no single ‘indigenous experience’ of palliative care.
- Until 1994 no Aboriginal deaths were recorded in hospices in South Australia
- Palliative care services specialise in providing care in relation to specific diseases, most of which are under-represented in indigenous communities, although cancer rates are increasing.
- Western concepts of ‘palliative care’ are almost unknown in indigenous communities, where family members have developed skills and knowledge around care for terminally ill relatives, but have not labelled this as ‘palliative care’.
- The transition from active treatment to a palliative care situation requires that patients and families be provided with culturally appropriate information to ensure that the implications of such a decision are fully understood.
- Serious concerns relate to the issue of the hospital as a focus for concerns around inappropriate treatment and the experience of fear of terminal illness within such a setting.
- Evacuation from remote communities to hospital, hospice and residential care is a complex and serious issue with implications for death occurring in, or away from, traditional country.
- Palliative care should not be seen in isolation from broader health policy and planning processes, and is linked to contextual socio-economic factors which influence social justice concerns.
- Training and education of indigenous communities, Aboriginal Health Workers, indigenous service providers, and non-indigenous health and medical staff is a vitally important prerequisite to the development of a strategy.
- Interviewing of indigenous people regarding palliative care needed to be conducted by indigenous researchers due to sensitivities around the project.
- Death and grief are a constant presence in indigenous communities, and grieving practices exist which are influenced by Christianity as well as traditional cultural practices. It is vital to ensure families and communities are supported and resourced to provide appropriate support to grieving families.
- Doctors frequently lack appropriate cultural understanding, communication skills and a willingness to relinquish expertise in relation to indigenous knowledge. Referral practices may result in patients choosing to avoid medical care.
- Elders play a significant role as palliative care advisers, including advising on grief practices, particularly in the Yorke Peninsular communities consulted.
- The incidence of premature deaths needs to be a future priority in the development of a palliative care strategy in remote areas. Consideration needs to be given to the implications of petrol sniffing, diabetes, alcohol consumption and violence and trauma for palliative care planning.
- The majority of deaths in communities are not associated with old age, which increases the likelihood that the death may have been unexpected, and grief may be unresolved. Youth-related terminal illness is a serious and complex issue.
- Appropriate settings for palliative care outside hospital contexts need to be identified, including community clinics, homes, camps and alternative sites.

- Strategy development must occur within a broader context of indigenous health policy and planning, with indigenous involvement in or control of the process if it is to be effective. Indigenous health and social service organisational partnerships with government, reflected in health policy frameworks, are a basis for such development.

b) Wagstaff, P (1997) *Appropriate Care: The Palliative Care Needs of Victorian Aboriginal People* Draft Report for the Victorian Department of Human Services

This is an unpublished draft report, and as such its status with the Victorian government is not clear. Never-the-less it raises several significant concerns related to indigenous palliative care issues in Victoria. The report refers to a State-wide Reference Group to be established as part of the Koori Services Reform Strategy as a source of ongoing monitoring and evaluation. Whether this group was established and incorporated a brief regarding palliative care is not clear. The document reports on research which aimed to develop guidelines for community-based palliative care services and support networks within the Aboriginal community. In addition to literature review and reference to studies in progress at the time of the research, including that by Reid and Prior, it contains detailed statistical information relating to morbidity and mortality rates. It comments on the lack of available useful data on Koori health data for monitoring and planning, including lack of statistics regarding Aboriginal usage of current services, due to non-recording of Aboriginality by service providers.

The researchers contacted palliative care organisations to assess usage of mainstream services and service providers' viewpoints. Many had had no contact with Koori clients, while two hospice organisations in the Northern suburbs had had Koori clients. Koori organisations and individuals were consulted. Conferences on Koori palliative care and Koori health issues were attended with workshops conducted by the researchers, including conferences organised by the Victorian Aboriginal Community Controlled Health Organisation Incorporated (VACCHOI) and the Victorian Aboriginal Community Services Association Incorporated (VACSAI).

A questionnaire was sent to a sample of rural palliative care services to assess their level of involvement with Kooris and their views. Very few or no indigenous people had been contacted by the six services which responded. Most supported the need for in-house training in Koori needs, and would support the appointment of a Koori representative on the boards of palliative care organisations at State, regional and local levels. A questionnaire was also sent to seven Aboriginal Hospital Liaison Officers who were funded to attend a State-wide conference.

It is unfortunate that the report's methodology section is clearly incomplete. As such, it is not possible to determine the precise composition of the research team, other than assuming that the researcher referred to in the preamble, who had contributed a great deal to the research process while herself suffering an illness which claimed her life during the course of the project, as well as the report's author, were members of the team. The appendices include questionnaires sent to rural services and Aboriginal Liaison Officers in hospitals, although the report contains little or no mention of the process of design of the schedules, data collection, or sample selection. It is also not possible to determine the ethical approval process which the research followed, other than the inclusion of the NHMRC's Guidelines (1991) as an Appendix. This is not to imply that ethical approval was not achieved, but to highlight the unfortunate lack of methodological information which could have been contained in a final report. The Terms of Reference for the study are not included.

Despite this, the report is both wide-ranging and comprehensive, including extensive contextual and historical information which frames the fourteen guidelines for indigenous palliative care. It draws a link between Koori palliative care needs and the Victorian Department of Human Services' Koori Services Reform Strategy 1997-2002, seeing the strategy, based on empowerment principles and emphasising community planning, as an appropriate mechanism for ensuring that protocols for indigenous palliative care are developed and monitored. It sees Koori community controlled health organisations as best placed to facilitate delivery of services in accordance with the strategy. It sees Koori involvement in planning, development and monitoring of palliative care as essential. It also sees cross-cultural training, education of Kooris and co-ordination of services as important priorities.

Significant Issues Identified in the report include:

- An understanding of the context within which dying occurs is vitally important if culturally appropriate services are to be provided. This involves an awareness of socio-economic, cultural, psychological and historical factors which play a role in the process of dying and in Koori experience with government policies and health professionals.
- The central role of the family within Koori culture, and the significant role of elders within the family structure should be recognised and strengthened in the liaison process between mainstream and indigenous organisations.
- The concept of community is of central significance, while there are many Koori communities, with autonomous and diverse organisations and groups.
- Attachment to land is of critical importance, and death and/or burial in traditional land following care in home communities is vitally significant for spiritual and community well-being. The Victorian Aboriginal Funeral Service plays a vital role in ensuring return to home community for burial. In addition, spiritual beliefs will vary between Koori groups, and assumptions about the identical nature of spiritual understandings should not be made.
- Socio-economic disadvantage results in severe financial, social and emotional hardship for carers and the terminally ill during the dying process. Family members may not have the resources required to be able to provide care at home. Premature deaths and high birth rates and personal ill health may increase the carer burden.
- A lack of awareness of the existence of palliative care services may be experienced by Koori people, and educational disadvantage may play a role in this.
- A serious lack of accurate statistics on morbidity, mortality and service usage results in estimates having to be made regarding the small numbers potentially requiring palliative care each year.
- The Koori need for grief and loss counselling services is likely to be high and critical.
- Aboriginal Liaison Officers in Hospitals need to be included as essential members of palliative care teams, ensuring that patients understand diagnoses and prognoses, and in particular providing support to patients when family members are not present. Koori HACC workers need to be included as community palliative care team members and regional Koori HACC and Disability networks need to play an advisory role to palliative care agencies.
- Community controlled health organisations need to be involved in palliative care planning, development and delivery, in accordance with the Koori Services Reform Strategy.

- c) Williamson, P (1996) *'Let Me Die in My Country': Palliative Care Needs of Aboriginal People in the Kimberley and Pilbara Regions of Western Australia* Final Report North West Aboriginal Health Strategies Unit. Broome.

Final report of a project which took place between October 1995 and June 1996, funded by the Western Australian Department of Human Services, and administered by the WA Health Department. The project aimed to develop guidelines for the establishment of palliative care services for indigenous people of the Kimberley and Pilbara regions. It involved an assessment of the level of awareness, including knowledge of available choices, on the part of indigenous people in regard to palliative care. It also sought to establish culturally appropriate guidelines for service delivery and management of patients in a variety of settings and to investigate educational needs of health professionals. A Consultative Group involving individuals nominated by communities and Aboriginal organisations provided advice on strategic approaches, development of a research instrument and recommendations arising from the findings of the consultations. A Project Officer and widely respected Aboriginal Health Worker conducted consultations with health professionals and indigenous people across over 40 communities and towns.

The overriding issue across all communities was the desire to die in traditional country, arising from concerns about the practice of evacuation of terminally ill people to regional centres or to Perth. Opinion was divided as to whether death in a hospice nearby to a community, or within a community itself was preferable. The importance of the involvement of traditional healers was emphasised, as was the use of bush medicines. A lack of morgue facilities in larger communities was identified as a concern.

A significant lack of awareness of palliative care issues was identified, on the part of both indigenous and non-indigenous people. Palliative care was administered on an ad hoc basis, without the level of information and support required, including information on choices and options available to carers and / or patients. Lack of communication to relatives from hospitals was a serious concern, related to the role of Aboriginal Liaison Officers. It was seen as vital that people leaving communities for treatment return for at least the last few weeks of life, and that families be kept informed regarding their relative's health status.

A need to establish a community-based support and information network across the region which would ensure delivery of local palliative care services was identified. A community based palliative care support group network was seen as an ideal model. Such groups were already operating in six centres throughout the regions. Strengthening of Aboriginal representation and resourcing levels of these groups was recommended.

A decentralised networked service able to respond to infrequent but intense demands was seen to provide an ideal solution to the issues affecting communities across a vast distance and to enhance the development of a model for cohesive servicing. Funded support groups across the regions, with strong Aboriginal representation as a condition of resourcing, could assist in meeting this need.

Aboriginal Liaison Officers could be actively involved in establishment and development of these groups, which would draw administrative and infrastructure support from, but not be combined with, aged care and HACC services. They would also play a significant role in the provision of information to carers and the training of non-indigenous health professionals. A diversity of local factors necessitates that each support group's detailed organisation would be decided by local people, reflecting that community's cultural requirements and attitudes. The report recommends that one of the groups adopt a co-ordination role across the network, providing advice on activities and funding and distributing resource

materials. This group would also maintain links with palliative care groups in other regions and interstate. It would also develop a program of seminars and education sessions, hold regular meetings, and send a representative to State and National meetings. Funding of the support groups would ensure that already overworked practitioners and professionals are able to provide services and support when required.

Significant Issues Identified in the report include:

- A serious lack of information, including awareness of pensions and benefits for carers was evident across the regions.
- Registers of palliative care clients, available resources and practitioners within regions should be established. A Standard Treatment Protocol could provide a guide and source of authorisation of treatment to nurses and health workers in remote communities. A Palliative Care Handbook would provide vital information on resources and sources of support for service providers and carers throughout the regions.
- Despite a lack of formal information, carers had developed knowledge and insight into providing care, including administration of medications.
- Lack of information to relatives from hospitals, including complete unawareness that a relative was dying, was a serious concern. Lack of flexible visitation access to hospitalised relatives was a serious problem. A need for a review of the roles of Aboriginal Liaison Officers was expressed.
- Transportation of bodies to communities from hospitals or temporary removal of bodies from communities disrupts ceremonial processes and is distressing. Small morgues could alleviate this problem where cause of death is not complicated.
- Grieving rituals are well developed and ceremonial rituals provide comfort and support to family members and the community. Support after death is a vital aspect of palliative care services.
- Nurses, health workers and Doctors across the regions were already providing information and training to assist families caring for dying people at home.
- Health and medical practitioners lacked access to information about advances in palliative care management and initiatives in other regions, reflected in a serious lack of resource materials.
- Educational institutions which train health professionals, as well as community health organisations and palliative care support groups need to ensure that indigenous palliative care education is incorporated into curricula and programs. Traditional healers need to be involved as trainers.
- The majority of people with terminal illnesses in communities were old, although aged care and palliative care are distinctly different.
- Vast distances and scattered population centres in a remote region render centralised hospice based services inappropriate.
- Decentralisation of a model of palliative care service provision is essential if it is to be appropriate and effective.
- Decentralisation would necessitate a flexible non-permanent staffing structure, as fluctuating needs would arise sporadically in specific areas.
- The need for palliative care will be intense and constant over a shorter period, while aged care services are less intensive and longer term.

- A flexible model could cater for a wide diversity of cultural priorities and attitudes to palliative care across the regions, and accommodate local needs, customs and beliefs.
- Palliative care needs are best considered within a holistic view of health and social care, in the context of support workers and health professionals as providers of a broad range of health services.
- No accurate figures exist for numbers of people requiring palliative care in the regions, although morbidity data suggest 15 to 20 people from the regions may be likely to require such care per year. This figure may represent an underestimate, as it is based on cancer rates and not on renal, respiratory, or emerging diseases including asbestosis.
- Separation from family, community and country is a serious concern and transportation to regional centres or to Perth can cause serious distress. Such a centralised system provides high level medical and pain related care while compromising social, emotional and cultural needs, including spiritual links to country.
- Traditional healers provide significant spiritual, emotional and physical support to the dying person and the family and are key people in the palliative care situation, where they are able to explain illness and interpret spiritual actions and supernatural forces and can advise if death is imminent. Their involvement from early stages of illness, at a patient's request, is vital.
- Concerns were expressed about 'noise, humbug and anti-social behaviour' in communities, and the effects of this on terminally ill people. Closeness to community and access to traditional healers were never-the-less seen as a priority.
- There are no palliative care support groups relating to remote communities across the regions consulted. A support group, established by a medical officer in Broome, funded through the National Palliative Care Program, has operated over several years. The establishment of similar groups in other regional centres had occurred at the time of publication of the report. The groups had not addressed the specific needs of indigenous people in towns or remote communities.
- Family members experienced severe distress at attempting to organise to meet the needs of dying relatives. Decisions were sometimes made without full information provided to the patient and family.
- Concerns over storage and administration of medications were raised by health professionals in remote communities, who saw these as best addressed through training and support by health practitioners and a support group.
- The concept of a network to complement existing medical and nursing services was strongly supported by indigenous and non-indigenous people across the regions. The resourcing and development of groups which exist, including establishing similar groups in new areas, was seen as more appropriate than the imposition of inappropriate models on an existing support system.

d) Collis-McAnespie, O. Dunn, P. Hemmings, L. Bell, P and Dawes, A (1997)
The Terminally Ill Koori: Their Care and Their Carers Australian Rural Health Research Institute, Charles Sturt University. Albury.

Qualitative research, undertaken by Collis-McAnespie, the first Aboriginal Health Education Officer in NSW with a specific brief in Palliative Care, was conducted through a partnership with the Macquarie Area Health Service and the NSW Aboriginal Health Resource Co-operative, under the auspice of the Rural Health Research Institute at Charles Sturt University. An Advisory Committee was established to guide the project and an RN with palliative care experience provided part-time research assistance. The research aimed to examine the needs of terminally ill Aboriginal people in North Western NSW, formerly Macquarie and Orana health districts. In addition it aimed to improve the provision of information to the terminally ill person, their family and carers, and to improve access to culturally appropriate palliative care.

The report includes a literature review which refers to issues including: the context of indigenous health and healing; the significance of traditional customs associated with death and dying; the issues surrounding hospitalisation of the dying; the medicalisation of the dying process in non-Indigenous settings; the many cultural approaches of Indigenous communities; lack of resources for appropriate services and the need for education and training. These themes are reflected in the results of the analysis of the notes from 29 open-ended interviews conducted by the researcher in 13 communities and towns. Ethical concerns were addressed through indirect approaches to participants through Aboriginal Health service providers, ensuring privacy and informed consent, allowing for interviews to be non-time limited and note-taking rather than recording interviews, on the advice of Aboriginal people.

The report presents an historical context within which issues related to the health and illness of the Aboriginal population can be understood. As such it links broader socio-economic and political factors such as poverty, forced removal and relocation of families and children, lack of access to employment and education and experience of racism to present day experience of terminal illness. It links lack of services providing sanitation and severe living conditions on reserves and stations to current day experience of illnesses such as renal disease, which can result in the need for palliative care.

Emergent themes around which the results and recommendations are presented include: Culture and Terminal Illness; Access to Services; Quality of Service; Carer Burden and Grief and Loss. In addition, two case study summaries are presented, and an overview of issues arising from a National Workshop conducted at the National Aboriginal Health Workers Conference in 1997 is provided. The issues raised at the workshop reflect those highlighted in both the literature review and the qualitative interview results, including cultural sensitivity, kinship, transport, medical staff, home support, information needs (including a Directory of services) and specialist training for Aboriginal Health Workers in palliative care.

Significant Issues Identified in the report include:

- Relevant literature identifies ‘profound cultural dissonances’ between Aboriginal and non-Aboriginal beliefs around health. One of the areas where this is most pronounced is in relation to death and dying.
- A history of racism, lack of freedom of movement and refusal of government to provide basic sanitary services, while removing children and transporting families, has resulted in a variety of serious health concerns and a seriously shorter life expectancy for indigenous people.

- Death rates vary across communities, ranging significantly from similar to those of non-indigenous people to many times higher, in different communities. Diseases of the circulatory, respiratory and digestive systems, injury and poisoning and cancer were the major causes of indigenous deaths in the area studied.
- Consultation with the major partners in the project resulted in a commitment to having an indigenous researcher employed to conduct all interviews for the project. Training in research techniques provided to the indigenous researcher and the research assistant was seen as essential to ensuring effective data collection.
- An open-ended interview structure involving conversational style interaction between the researcher and the participants was considered culturally sensitive and proved to be appropriate to ensure a depth of quality of data.
- Although the project was small scale and did not claim generalisability, it collected data which were experientially valuable and reflected indigenous people's concerns and knowledge.
- While there was a lack of information apparent around some palliative care issues, a strong theme of self-reliance emerged, which involved families attempting to keep care 'within the family' for as long as possible, even when aware of health services. This was seen to decrease potential conflict with non-indigenous health providers, particularly in hospital settings.
- Participants had accessed a wide range of services and were generally informed about the role of service providers through General Practitioners or Aboriginal Health Education Organisations, although transportation to services was a problem.
- The role of the Aboriginal Medical Service was a source of confusion and frustration, with the view expressed that local politics, nepotism, lack of communication and confidentiality issues resulted in people expressing frustration and anger towards the service. A need for the service to clarify and communicate its role to the community was recommended.
- Medical practitioners and palliative care nurses were seen as supportive and vitally important, although this was not the case for those in hospitals, who were seen to be problematic and inappropriate in their approaches to family and patients.
- Aboriginal Health Workers' roles were seen as critically important, including the need for someone to provide family with emotional support and comfort during and after death. Their training needs require skills development in palliative care and grief issues.
- Information about treatment, illness, prognosis and care options was often inadequate, although some participants felt well informed.
- Fear around death and burial away from home town or birthplace was a serious significant concern, impacting on conscious decisions to avoid formal health services.
- Carer burdens, including emotional drain, social isolation and financial hardship, are a significant concern and need to be investigated by government and indigenous organisations.
- Cultural responses to spiritual matters will vary considerably, and may even present completely opposing viewpoints. Assumptions which generalise across indigenous communities are based on false understandings.

Rural and metropolitan health service providers require protocols to ensure effective transfer of information when terminally ill people move between locations.

e) Prior, D. (1999). 'Palliative care in marginalised communities [Review].' *Progress in Palliative Care* 7(3): 109-115.

Prior, D. (2001). 'Cultural Safety in Palliative Care Issues for Research and Practice.' *Palliative Care News Exploring Indigenous Palliative Care* (Winter 2001).

Deborah Prior has conducted important research related to Indigenous palliative care focussing on issues around Indigenous people's concepts of palliative care and the provision of culturally appropriate palliative care. She had also published on Indigenous palliative care issues in journals and newsletters, and has contributed significantly to education of service providers and quality improvement in the field.

Deborah Prior's thesis research was completed in 1997. The research aimed to find out from Aboriginal people what issues needed consideration in the development of culturally appropriate palliative care services in urban communities. Prior used an ethnographic approach, a method strongly related to anthropology, involving spending time within a site or a group, observing, participating and interviewing. She undertook this work in several Aboriginal health care centres, and one residential facility for elderly and sick indigenous people. She also accessed written documents relevant to the research, through staff and other sources.

Her key findings included the incongruence between Anglo-Australian approaches to palliative care and indigenous people's desire for self-determination, as well as the inappropriateness of concepts such as terminal illness to indigenous people. She recommends a review of assessment procedures, culture-centred approaches to grief counselling, and education of non-Aboriginal staff, all of which she sees as contributing to indigenous influence on palliative care development.

While the thesis itself is certainly worth a look for anyone with a keen interest in the detail of the research and the findings, Prior has provided a valuable and accessible overview of the implications of her findings in a number of publications in journals and newsletters, including *Palliative Care Australia's Newsletter*.

Her article in *Progress in Palliative Care* draws on her research findings, focussing on the idea of marginalisation, seeing it as taking place in relation to factors such as imprisonment, geography and culture. She refers to people who do not have cancer as being marginalised within palliative care, in that there has been a heavy emphasis on cancer as a basis on which people are provided with palliative care, including care in a hospice. She describes her research as 'a study about the meaning of palliative care to an Australian Aboriginal community' and describes culture as 'a system of meanings'.

Linked to this is a concept integral to her research and writing – cultural safety. Prior refers to Maori nurses developing this idea as an element of healthcare in the 1980's, seeing physical, emotional and cultural safety as logically related to standards of care. Cultural safety is distinguished from the idea of cultural awareness or sensitivity, in that it involves more than just an acknowledgement of cultures other than the dominant culture, and promotes the distinction between cultures in a deliberate way. Cultural safety requires that change take place in the healthcare system so that culturally 'unsafe' actions, which 'diminish, demean or disempower cultural identity' are minimised.

Prior points out that the WHO Principles for Palliative Care do not emphasise culture, merely implying it, and sees this as potentially leading to risks that specific cultural needs will be overlooked, incorporated into 'spiritual' or 'psychosocial' needs, which often require a cultural context to be understood. She contrasts Aboriginal and non-Aboriginal value systems and world views about health and illness,

referring to misunderstandings which can occur when cultural differences are ‘accommodated’ in palliative care. As she puts it: ‘...efforts to bridge cross-cultural barriers can go to extremes with overzealous interventions from a well-meaning team of specialists’. She cites examples of use of interpreter services, cultural brokers and translation of brochures as outcomes of a tendency in palliative care to ‘accommodate’ cultural difference.

A starting point to developing cultural safety, Prior says, is understanding and respecting different cultures. The history of cultural contact and colonisation in Australia is integral to an understanding of cultural barriers in palliative care. The activation of strategies to promote and nurture the unique cultural identity of the patient (such as understanding concepts of health and illness) are the essential second step to cultural safety, according to Prior.

The article outlines each of four ‘cultural themes’ which can guide the application of principles of cultural safety in palliative care – beliefs about illness, dying and death, folk and popular healthcare practices, language and cultural practices (ritual, ceremony), and social organisation (family, community). Prior looks at each of these in relation to Aboriginal culture, drawing strong contrasts between Western and indigenous perspectives and definitions and emphasising the body-mind-spirit connection in indigenous health concepts.

She refers to notions of ‘terminal illness’ as incongruent with the life-death-life continuum of Aboriginal spirituality. At its most simplified, Prior refers to the need to ‘learn about different cultures by simply asking the people’. Here she is clearly not advocating that all healthcare practitioners rush palliative care patients with questions, but rather refers to the recommendations of the Royal Commission into Aboriginal Deaths in Custody which emphasise the importance of consultation and self-determination.

In her article in *Palliative Care News* and her chapter in *Palliative Care Nursing: A Guide to Practice*, Prior reiterates the important concept of cultural safety, making a significant distinction between a common health provider perspective which sees all people as individuals, potentially negating cultural differences, and one which acknowledges that culture is a vital part of individual identity. Service providers’ claims to be seeing each individual as ‘unique’ are based on assumptions about people being culturally in tune, comfortable and open in their relationships, and mutually respectful, when this may not necessarily be the case. In fact, as she puts it ‘indigenous people may not even want this type of relationship’.

Prior points to important factors which need to be considered in research and service development in indigenous palliative care, including indigenous control of methodology and policy development. She identifies a scarcity of relevant research and of references to palliative care in health policy, both of which the Scoping Study aims to assist to redress. Her involvement in the education of palliative care nurses, as well as her active input into PCA and the Palliative Care Council of Queensland is evidence of her commitment to see the outcomes of her research translated into benefits for indigenous people and service providers in palliative care.

f) Fried, O. (1999). 'Many ways of caring: reaching out to Aboriginal palliative care clients in Central Australia.' *Progress in Palliative Care* 7(3): 116-9.

Fried, O. (2000). 'Providing palliative care for Aboriginal patients.' *Australian Family Physician* 29(11): 1035-1038.

She has conducted important research related to Indigenous palliative care focussing on issues around Indigenous people's concepts of palliative care and the provision of culturally appropriate palliative care. She had also published on Indigenous palliative care issues in journals and newsletters, and has contributed significantly to education of service providers and quality improvement in the field. Dr Fried completed her PhD investigating issues related to indigenous palliative care in 2000.

In her article in *Progress in Palliative Care*, she refers directly to Deborah Prior's concern that the concepts and principles of palliative care might be inappropriate for adaptation to a non-indigenous situation. Fried, on the other hand, sees the work of the Palliative Care Service in Central Australia as necessarily assuming that adaptation of the principles is possible, and can be of benefit for indigenous patients and families requiring palliative care.

Although Ofra Fried does not draw directly on Deborah Prior's idea of 'cultural safety', the process which she describes in her article could be interpreted as one of enhancing cultural safety through the development of culturally appropriate education programs. Fried refers to the principle of equitable access to palliative care, seeing the development of a local cross-cultural promotion project as congruent with this notion.

Fried describes the process and outcomes of the project '*Many Ways of Caring: the Central Australian Palliative Care Aboriginal Paintings Project*', initiated by the Central Australian Service and closely involving local Aboriginal artists. She also refers to the project in her articles in *Palliative Care News* and the *Menzies School of Health Research Newsletter*. That the process by which the project unfolded, as well as the outcomes it created, involved a strong commitment to indigenous input and culturally appropriate education was vital to its value and long-term usefulness.

Fried acknowledges that the model of palliative care which best suits indigenous people has yet to be developed, but emphasises that projects such as the paintings initiative are steps towards the development of access to and shaping of more appropriate services.

The project drew upon the prominence of graphic art as a mechanism for Aboriginal communication of ideas and narratives about significant issues, including health matters. Four women from the Jukurrpa Artists' local organisation were commissioned to paint about 'looking after people when they were finishing up'. The approach was made on the advice of the Liaison Team at the local hospital, and one artist, Maudie Napanangka Nelson, a former liaison officer, provided interpreting assistance with the process of commissioning. Four women, Bessie Liddle, Kitty Miller, Rachel Napaljarri Jurra and Maudie herself, produced paintings with accompanying stories concerning palliative care issues.

Common themes across the paintings include: the significance of family decision making; the patient's choice of environment in which to receive care; the role of family members and the role of medical and health service staff and non-indigenous service providers. The relationship between traditional and Western biomedical models of care was also a prominent theme.

The paintings have been used as a tool for practical educational purposes, including being on display in a local shopping centre, a process which triggered both Aboriginal and non-Aboriginal responses. A poster and a series of brochures were designed and distributed. Education of groups of student nurses and

doctors as well as Aboriginal health workers has included the paintings as a mechanism for discussion of palliative care issues and cross-cultural appropriateness of service delivery.

Fried describes the process as ‘opening a door’ to the Aboriginal clientele of the Palliative Care Service. Such a process would undoubtedly serve to enhance the experience of ‘cultural safety’, given the extent to which the process was determined by and sat firmly within the context of the local community’s commitment to self-determination. Perhaps this is the key to enhancing, rather than merely accommodating, cultural difference, in that it demonstrates that the ‘how’ as well as the ‘what’ of the development of appropriate services are both equally important.

In her article in *Australian Family Physician* Fried raises options and outlines suggestions for non-indigenous practitioners in palliative care to consider in order to work towards providing appropriate cross-cultural palliative care. The article is based on her own experience in palliative care delivery. She refers to the principle of equity of access, seeing it as necessary to consider a patient’s unique circumstances if such a principle is to be applied. Again, while Deborah Prior sees non-indigenous, Western principles as inadequate and potentially inappropriate,

Fried sees the issue of equity as directly relevant to indigenous palliative care, particularly through its application to the education of non-indigenous practitioners in primary health.

She outlines some of the myths surrounding indigenous people and palliative care, including the belief that people do not often die of cancer, which she claims is actually common amongst indigenous people, although it is one of a range of terminal illness which people experience. She recommends that service providers need to learn about their patient community, improve referral practices and accommodate their service to the needs of the population.

Crucial to this is that providers of service need to work through existing Aboriginal service providers, including incorporating this into an examination of their own personal beliefs. This, she says, will ensure a basis for humane services. She emphasises that the relationship between the practitioner and patient takes place within a broad cultural, historic and socio-economic context which cannot be swept aside or ignored. She acknowledges that most practitioners like to be in control and are not experienced at sharing power! Even so, Fried recommends that the challenge to develop cross-cultural appropriateness in the approach one takes to providing services is one that medical and health service providers must take up.

She provides examples from Central Australian experience around care planning, decision making, bereavement, and working with indigenous colleagues and families. Her advice to practitioners, combined with her overview of the paintings project evidence that the Central Australian Palliative Care Service is committed to a process which aims to provide, or enhance the provision of, culturally appropriate palliative care services.

2.0 Abstract – Fried 2000

Fried, O. (2000). *Cross cultural issues in the medical management and nursing care of terminally ill Aboriginal people in Central Australia*. Menzies School of Health Research, Alice Springs and Faculty of Medicine, University of Sydney: 279.

This research documents, for the first time, the experiences of non-Aboriginal primary health workers caring for terminally ill Aboriginal patients in Central Australia. Despite the high mortality amongst Aboriginal Territorians, issues around terminal illness, death and bereavement have been little studied. The area is sensitive in both cultural and human terms. Many clients of the local health care services are Aboriginal people whereas most nurses and doctors are non-Aboriginal. Their clinical interactions are inherently cross cultural and are additionally influenced by several sequelae of Australian colonial history, including socioeconomic and status disparity between participants and entrenched discriminatory attitudes and practices.

The study was approached from the perspective of the new public health, informed by the philosophy of contemporary palliative care and aimed to contribute to the development of a culturally safe practice for the care of terminally ill Aboriginal people. Data was collected using a qualitative method of serial interviews with a representative sample of primary health care workers with an Aboriginal clientele.

The study found that cultural factors were important determinants of good health care communication, the making of appropriate end-of-life care decisions and the provision of quality case management and bereavement support. Significant cultural issues for achieving a 'good death' included recognition of the wish of many Aboriginal people to die on their own country and of the value of the Aboriginal kinship system for enabling care decisions and providing care. To date however, these have had little formal impact on the design or delivery of health care services for terminally ill Aboriginal people in Central Australia.

Nurses and doctors interviewed for this study considered Aboriginal patients' access to quality health care during a terminal illness to be inadequate and inequitable. The difficulties of providing health care in remote areas impacted disproportionately on Aboriginal clients. Their treatment options were limited by their poverty and by

institutional policies determining the availability of resources. Cultural and language miscommunication between Aboriginal clients and non-Aboriginal health professionals impaired the process of decision making and the delivery of care. The hegemony of the majority culture and its health care institutions disempowered Aboriginal clients while entrenched discriminatory social attitudes perpetuated inequitable practices. Specific *service gaps* were identified in the availability of interpreter services, transportation, respite care, domiciliary nursing and bereavement support. The wider care network, including hospitals, nursing homes, multidisciplinary health care providers, and the transport needed for remote clients to access these, was inequitably available and insufficiently accommodating of Aboriginal cultural needs. The existing palliative care services employed no Aboriginal staff. Improving care will therefore require a range of institutional and societal responses, including addressing service gaps, providing practical responses to cultural aspects of service provision, and continuing to work towards reconciliation.

A major deficit was found in the training and support available to practitioners caring for terminally ill Aboriginal people. Addressing this requires a policy shift by health care institutions. The most useful training interventions included directing non-Aboriginal workers toward local sources of cultural

information, dispelling myths and stereotyping and assisting in exploring ethical issues arising from cross cultural conflict. Practitioners also needed support both in analysing difficult care situations so as to arrive at practical management solutions and in debriefing their emotional responses. This would reduce the stress of providing cross cultural terminal care and improve service delivery.

Palliative care in Central Australia can only be developed with input from both Aboriginal and non-Aboriginal participants. It cannot be progressed without the guidance and support of Aboriginal workers and community members, which requires Aboriginal empowerment at all levels of planning and decision making. This reflection on the nature of cross cultural terminal care, from the viewpoint of professionals within the majority culture, will contribute to the development of a culturally safe practice for working with Aboriginal colleagues and clients.

Appendix 6



Methodology

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Field Methodology

Project Title: National Indigenous Palliative Care Scoping Study
Research Organisation: Kate Sullivan & Associates Pty Ltd
Funded by: The Australian Government Department of Health and Ageing

Prepared for submission to the
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11 June 2002

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Note: Since this proposal was submitted some terminology has been modified to conform with a request from the NH&MRC (NSW) (ie the term ACCHS has been used though out). The South Australian Ethics Committee requested some clarification about sample size which was provided by letter. The Western Australian submission complied with the WA format requirements, though the substance was the same). Attachment D3 was later simplified to incorporate the signed consent into question sheet proper. Field destinations were finalised subsequent to this proposal so attachment C does not describe final destinations.

1. INTRODUCTION

The Australian Government Department of Health and Ageing has funded a national study into Indigenous Palliative Care. The main aim of this project is to find out:

- what palliative care services are available for Aboriginal and Torres Strait Islander peoples,
- how well Aboriginal people can access services and whether they are suitable for their needs,
- whether improvements could be made,
- whether there are areas where needs are not being met.

The purpose of the study is to make sure that the National Palliative Care Strategy adequately takes account of Indigenous issues. Kate Sullivan and Associates Pty Limited is the consultancy firm which is undertaking this research for the Australian Government.

The project has four broad stages:

In **Stages 1-3** (March-April 2002) there was a literature review (looking at previous research and other documented activities) and scoping study, which involved contacting State and regional agencies, service providers and community organisations by telephone and talking with them about palliative care services in their regions.

Stages 4-5 (May-June 2002) focus on developing methodology (the steps that will be followed when visiting and talking with communities and organisations) and building partnerships with communities which consultants will visit later.

During **Stages 6-7** (July-October 2002) fieldwork will be conducted. This will include rural and remote areas and some towns or cities, and will be done by male and female team members. A question sheet will be posted to community organisations in selected communities that cannot be visited.

Stages 8-9 will be the reporting phases. The final report will be in two parts – a detailed report for the Australian Government Department of Health and Ageing, and a short report which will be given to all communities and organisations that have participated in the study.

Field work methods will be agreed with communities and approved by appropriate ethics committees. The researchers will make sure they have consent of communities and individuals who take part in the study, and will ensure that any personal information provided is kept confidential.

This submission addresses Stage 4-5 and Stages 6 and 7 of this project, ie fieldwork and questionnaire development and implementation.

2. NATURE AND BENEFITS OF THE FIELD RESEARCH

a) Outcomes and Benefits

The research is social policy research focussing on questions of appropriate service delivery. The research applies sound social research principles, is ethical and is designed to be culturally sensitive. The outcome of the project is to advise and inform the Australian Government Department of Health and Ageing regarding service delivery needs and issues, in order to:

- Inform the National Palliative Care Strategy and ensure it takes account of Indigenous Issues
- Inform the development of a set of Guidelines and training materials for all palliative care service providers which is being developed under contract for the Australian Government by a partnership between Wodonga TAFE and the Mungabareena Aboriginal Corporation. These guidelines and teaching materials will aim to improve the appropriateness of service delivery to Indigenous clients.

It is our intention to negotiate with each community or organisation on how they might like the results of our research into their particular situation presented so that it may be of some immediate use to them.

b) Community Control

Community control of the project is built in in a number of ways.

- The Partnership development process being undertaken in the current stage will ensure that community wishes are incorporated in to the methodology and into the reporting process. Partnership agreements will be developed with communities or organisations who are willing to take part in the research. (See letter at Attachment A).
- The proposal will be submitted for ethics approval to each state ACCHS body.
- Consent forms (organisational and individual) will be used at all interviews and discussion groups and with any questionnaires developed (see Attachment B1). An ‘Informed Consent Statement’ (Attachment B2) has been prepared to be read to participants in front of a community witness, in the event that a participant is uncomfortable reading a consent form.
- We are specifically asking participants how we can make the research immediately useful to them. Reporting formats and opportunities for comment on data interpretation as desired by participating communities and organisations will be incorporated into the partnership agreements. In addition, our contract with the Australian Government specifies that a short ‘plain English’ report is to be provided to all participants at the end of the project.

c) Cultural Sensitivity

The subject matter is a very sensitive one, and the project is a national project. The regional variations in Indigenous traditions and terminology mean that the question sets outlined in this proposal should be considered as ‘draft’, as they remain to be tested and checked at a number of levels.

- Considerable investigation and discussion has already taken place regarding an appropriate form of words to be used in researching in the area of Indigenous palliative care. This varies from community to community.
- The methodology has been checked by the Indigenous members of our team, and by the Indigenous members of our Steering Committee, and the form of words will be tested in a number of settings.
- Wording of questions will be checked at each field location with appropriate organisations and local Indigenous advisers to ensure that the language is appropriate at the local level. If necessary, modification to the form of words will be made at that level. The intent of the questions will be maintained.

3. RESEARCH BRIEF

Three types field work will be conducted:

- Regional Needs Analysis
- Good Practice Studies and
- Facilitation of protocol development (at present one location only is planned in Victoria)

The possible locations for these types of field work throughout Australia are appended at Attachment C. In the case of organisations which we would like to include in our field work but which we cannot visit (due to logistics or budget) a question sheet which mirrors the information being collected (and headed by an informed consent form) will be forwarded for completion, and/or the questions will be asked by telephone (see Attachment D3). N = >50 < 100.

Fieldwork will involve the sorts of enquiries set out below.

a) Regional Needs Study

Where will the field work be done?

Regional needs analysis will be conducted in several regions that are known to have a relatively high Indigenous population, but where little is known about palliative care service delivery to Indigenous people.

Line of enquiry

The research will aim to develop a picture of what palliative care services are available. How are they accessed by the wider community? How are they accessed by Indigenous people? Identify needs and unmet needs.

Who will be interviewed?

Any or all of the following:

- All mainstream palliative care providers in the area
- Primary health care providers
- ACCHSs
- Hospitals
- ALOs
- Community Health Centres
- HACC workers and Indigenous Community Aged Care Package providers
- Aboriginal or Torres Strait Islander community organisations
- Members of community with experience of the palliative care system and/or who can share their experience of looking after family who have incurable illness. N = minimum of 5 and maximum of 15.

The sorts of questions which will be asked

Questions are set out in Attachment D1. Changes to these questions will be made only for clarity or cultural sensitivity. The scope and intent of the questions will be maintained. Some specific terminology may need to change depending upon local advice.

Identifying Barriers

Where we identify barriers to Indigenous peoples accessing mainstream services we will ask: 'what would need to change for you to approach a mainstream service?'

Community resources and payment for services

We do not expect that we will require the use of any community resources, unless these are specifically offered by the community or paid for by us. We expect that we will need the services of local Indigenous people to assist with setting up meetings and/or to help with the research in some areas. Where this is the case remuneration will be paid.

Outcomes

- Understanding the needs and unmet needs within a region.
- Documentation of community views about how these needs should be met.

Field time

3-5 days in the field, between July and September.

Approval of methodology

In June 2002, our methodology will be presented to the Aboriginal Health and Medical Research Council AHMRC (NSW) Ethics Committee for approval. We are also consulting with each of the other State level ACCHS umbrella bodies about their ethics requirements.

b) Good Practice Service Provider Study

Where will the field work be done?

Areas where we have reports of good practice (ie some services provided will be studied and unmet needs identified).

Line of enquiry

Areas of enquiry will include:

- Referral process
- Coordination with other services
- Palliative care specialist support availability
- Staff and training levels
- Cultural appropriateness

- Implementation of cultural protocols in service delivery
- Symptom management
- Physical needs
- Counselling and or grief/loss issues
- Funeral issues

The study will investigate how services compare with Palliative Care Australia (PCA) standards and enquire into the appropriateness of PCA standards from the viewpoint of the service provider and the community it serves.

Some studies might also examine 'Good Practice' in planning for or developing protocols for the delivery of palliative care services to Indigenous clients.

Who will be interviewed

- Service Providers who have been identified in initial scoping as 'good practice' providers;
- Other service providers with whom these services co-ordinate;
- Community members with experience of palliative care services. N = minimum of 5 and maximum of 15; and
- Relevant community organisations and opinion leaders.

The sorts of questions which will be asked

Questions are set out in Attachment D2 Changes to these questions will be made only for clarity or cultural sensitivity. The scope and intent of the questions will be maintained. Some specific terminology may need to be changed depending upon local advice.

Outcomes

- Understanding how the service model works
- Documentation of good practice service models
- Review of suitability of PCA Standards

Field time

Approximately 3 days in the field, between July and September.

Approval of Methodology

Our proposed methodology will be presented for approval to the Aboriginal Health and Medical Research Council AHMRC (NSW) Ethics Committee in June 2002. We are also consulting with each of the other State level ACCHS umbrella bodies about their ethics requirements.

4. RECRUITMENT OF COMMUNITY MEMBERS FOR DISCUSSION GROUPS OR INTERVIEWS

Recruitment

A local Indigenous community organisation (probably a Community Controlled Health organisation where these exist) or a local Indigenous adviser will be engaged to recruit participants using a Recruitment Guide (see Attachment E). The standard recruitment rate will be \$10 per participant recruited.

A media strategy (see Attachment F) is in place which will inform the general Indigenous Community that the fieldwork will be taking place. News items will identify the locations we will be visiting and will invite community members to contact us on our 1800 number if they would particularly like to have an input. Volume 2 of our newsletter, which reaches all ACCHSs, Indigenous HACC workers, and Indigenous residential and nursing homes, will carry the same message.

Group Structure

Interviews will be conducted as either one-on-one interviews, or in small discussion groups, depending upon the location and the interviewees' availability and preference. Our preference is for small discussion groups, but this may not always be possible. The same interview instrument will be used.

No one who has suffered a close bereavement in the last 6 months will be interviewed or included in discussion groups. The recruitment instructions for individual interviews and discussion groups (Attachment E) specifically excludes participants who have had a close bereavement in the last 6 months. A statement to this effect is also included in the consent form.

Whilst we will aim for age and gender balance, the primary consideration will be experience of the palliative care system or of caring for a family member with a life limiting, incurable illness. The sensitive nature of the research is to be made clear to potential participants and no one will be pressured to take part. Group size will generally be about 5. There will be opportunity for some one-on-one interviews if people want to talk to us but do not feel comfortable in a group.

We do not intend to interview any ill or frail people. If such people volunteer their participation and especially want to speak with us appropriate arrangements will be made with their medical carers.

Compensation for participants

Participants at focus groups will be compensated for costs involved in attending. An allowance of \$40 per participant is budgeted.

5. INFORMED CONSENT AND WITHDRAWAL OF CONSENT

We understand and support the right of participants to be fully informed about the research and to freely consent to take part. We support the right of participants to withdraw at any time. Consent forms based on the AH&MRC consent forms will be used, (See Attachment B) or a 'Statement of Informed Consent' will be read and agreed in front of a community witness in cases where literacy is an issue.

6. RECORDING AND SECURITY OF DATA

Recording of data

In general, interviews and discussion groups will be recorded by note taking. Recordings will be made with the permission of participants solely for the use of the note taker in reviewing the accuracy of their notes. Tapes will be forwarded with completed notes to Kate Sullivan and Associates' office to be erased. If any participant in a group objects to tape recording no recording will be made.

No photographs will be taken as part of the research as such and none will be included in the final report. Some photos will be taken for use in Newsletters 3 and 4. These photos will only be taken where written permission is given and a separate Photographic Consent Form will be used see Attachment G. No photographs will be taken without prior consent, and no photographs will be published without prior consent.

Confidentiality

Confidentiality will be maintained. Names of community participants will not be attached to records of interview. Care will be taken so that individual stories can not be linked to identity or location.

Case materials identifying location will not be documented in such a way as to reveal locations, unless the community and participants involved have specifically agreed to the case material being documented in this way.

Data Storage and Security

Data will be stored in secure locations. Raw data will not be stored for use in any other project. Findings of the study (with only de-identified material unless expressly agreed in writing) will be available to the Australian Government Department of Health and Ageing. They intend to use the information to inform the National Palliative Care Strategy and the development of a set of National Guidelines for Palliative Care service providers and associated training materials. No raw data or any material revealing participant identity will be passed on unless this has been agreed in writing. The consent statement and brief attached to the Consent Form will make the future use of the material clear.

Data will not be placed in any data base which could be linked to multiple or any other data base.

Disposal of Data

Raw data (interview, field notes, forms etc) will be securely stored at Kate Sullivan and Associates' office for 2 months following the final report (March 2003) and will then be shredded. Taped material will be forwarded to Kate Sullivan and Associates along with the completed interview notes and the tapes will be erased as soon as they are received. Data summaries (the data on which the report is based) will be burnt to CD Rom and stored in a locked filing cabinet at Kate Sullivan and Associates for 5 years.

7. DISSEMINATION OF FINDINGS

Immediate feedback to individual communities

Indigenous organisations taking part will receive summary finding notes pertaining to their input before these are incorporated into a final report. The form of these notes will be negotiated with each community or organisation as part of the partnership development before fieldwork.

Final report

The release of the final report will be in the hands of the Australian Government Department of Health and Ageing. There is no arrangement regarding publication.

A short plain English summary of the findings of the study is to be provided to all participants at the end of the project. This community reporting was initiated by us as part of our tender and is part of our contract with the Australian Government.

8. WHO WILL UNDERTAKE THE FIELD RESEARCH

The research team

The National Indigenous Palliative Care Needs study is being done by Kate Sullivan & Associates Pty Ltd. Kate heads a team of consultants with many years' experience in working with Aboriginal and Torres Strait Islander communities. The team includes both Indigenous and non-Indigenous people.

Kate has a wide range of experience in environmental and heritage management, local government and community development. Kate worked at senior executive level in the NSW Public Service before starting her own consultancy business in 1991. Some of the major national projects she has worked on include developing an information kit for Indigenous carers throughout Australia, and conducting research for the Australian Bureau of Statistics to find out what people think about the Indigenous status question on the Census form, and their experience of being asked this question in places like hospitals.

The other consultants working on this project have a broad range of experience. The consultancy team includes:

- **Jack Harradine** grew up in an Aboriginal community in South Australia. He is an accredited counsellor who has travelled widely throughout Australia and worked at senior levels of the Australian Government public service. He is currently based in Canberra.
- **Jennifer Beale**, a Gamillaroi woman whose background is in health, adult education and community development, has worked extensively with Aboriginal communities in Western Sydney and the Torres Strait.
- **Jack Gibson**, a Ngunawal man who specialises in community development, research and training, will act as adviser to the project.
- **Claire Colyer** has a background in journalism and public affairs and has worked with a number of central Australian and national Indigenous organisations.

- **Jo Harrison** has worked with many community-based Aboriginal organisations in central Australia in direct service provision, advocacy, training and research. She set up the Central Australian Advocacy Service and has written about issues affecting return to country to die.
- **Luana Johnston** is the Director of Bushwork Consultants which works primarily with Indigenous client groups in community development and organisational management. Luana has lived and worked with many Indigenous communities in central and northern Australia.
- **Jon Willis** is a senior adviser to the project. Jon's background is in health and cross-cultural liaison. He spent many years in central Australia and is the author of *Dying in Country: Implications of culture in the delivery of palliative care in Indigenous Australian communities*.
- **Ronald Harrigan** is based in Cooktown and is an experienced Aboriginal Health Worker. Ron will assist with field work in the Cape York area.

The field research

All field work will include Indigenous field researchers, with members of our own team and/or locally employed researchers.

In NSW research will be undertaken by Jack Gibson and Jennifer Beale with assistance from Kate Sullivan in the metropolitan area.

Luana Johnston will undertake research in Queensland, the Northern Territory and the north of western Australia, working with Ronnie Harrigan in North Queensland and with locally recruited Indigenous researchers in other areas.

Jack Harradine and Kate Sullivan will conduct field work in South Australia.

Kate Sullivan will work with local Aboriginal researchers in the southern part of Western Australia.

ATTACHMENT A

Fieldwork letter – first approach to community organisations

Dear ACCHS or Community Organisation or Service Provider

As you may be aware, the Australian Government Department of Health and Ageing has funded a national study into Indigenous Palliative Care. The purpose of the study is to try to find out about current services and needs and to make sure that the National Palliative Care Strategy adequately takes account of Indigenous issues. Kate Sullivan and Associates Pty Limited is the consultancy firm which is undertaking this research for the Australian Government.

The enclosed newsletter outlines the project and introduces some of our Indigenous and non-Indigenous team members.

We have now reached Stage 4 of the project and are beginning to plan the field work stage. We have identified a small number of regions, organisations or communities which we would like to approach about possibly taking part in the field work. This would involve us visiting the community or organisation for discussions about Palliative Care, about what services there are and what needs exist.

The purpose of this letter is to ask you for an early indication of whether you would welcome a visit from us and be able to take part in our research, providing issues of timing and budget will allow.

Before visiting we intend to develop 'partnership agreements' which will clearly set out what would be involved in the visit and confirm agreements that have been reached beforehand about issues such as:

- Agreement to take part
- Agreement of the consultants to any protocols required by the community
- Agreement to the length of the field visit
- Agreement with the methodology (see attachment)
- Fees to be paid for assistance with setting up meetings, introductions for interviews and focus groups, and for local advisers and researchers where used
- Payment for venues and catering where relevant
- The time frame and format in which the community/organisation would like to receive feedback
- Protocols about future use of the information collected

Further information about the methodology we will use – that is, the approach we will take and the kind of information we will be asking for – is explained in the attached sheet, headed 'Methodology'. We are in the process of seeking ethical approval for our methodology from relevant bodies (eg the Aboriginal Health and Medical Research Council in NSW).

We would also welcome your advice about other service providers and /or community groups in your area that we should also visit or interview.

If your community or organisation is interested in taking part, we would also like to discuss with you ways that we may be able to make the research immediately useful to you and to the community you serve. We do not intend to make promises that we cannot keep, so for example we could not promise any increased funding. However, it may be that our findings could be written up in a way that could be useful for you, for instance to develop protocols or assist coordination, make submissions or develop information packages and strategies.

One of our team members will contact you soon for preliminary discussions about the possibility of your organisation or community being involved in the field research program.

If you have any concerns or queries about this matter please telephone me on 1800 810 234.

We are looking forward to speaking with you soon.

Sincerely,

Kate Sullivan
Executive Director

■ METHODOLOGY: Regional Needs Study

We are currently developing our methodology and expect that it will involve the sorts of enquiries set out below.

Where will the field work be done?

Regional needs analysis will be conducted in several regions that are known to have a relatively high Indigenous population, but where little is known about palliative care service delivery to Indigenous people.

Line of enquiry

- The research will aim to develop a picture of what palliative care services are available. How they are accessed by the wider community? How they are accessed by Indigenous people?
- Identify needs and unmet needs.

Who will be interviewed?

Any or all of the following:

- All mainstream palliative care providers in the area
- Primary health care providers
- ACCHS's
- Hospitals
- ALOs
- Community Health Centres
- HACC workers and Indigenous Community Aged Care Package providers
- Aboriginal or Torres Strait Islander community organisations
- Members of community with experience of the palliative care system and/or who can share their experience of looking after family who have incurable illness.

Identifying Barriers

Where we identify barriers to Indigenous peoples accessing mainstream services we will ask: 'what would need to change for you to approach a mainstream service'

Community resources and payment for services

We do not expect that we will require the use of any community resources, unless these are specifically offered by the community or paid for by us. We expect that we will need the services of local Indigenous people to assist with setting up meetings and/or to help with the research in some areas. Where this is the case remuneration will be paid.

Outcomes

- Understanding the needs and unmet needs within a region.
- Documentation of community views about how these needs should be met.

Field time

3-5 days in the field, between July and September.

Approval of methodology

In June 2002 our methodology will be presented to the Aboriginal Health and Medical Research Council AHMRC (NSW) Ethics Committee for approval. We are also consulting with each of the other state level ACCHS umbrella bodies about their ethics requirements..

■ METHODOLOGY: Good Practice Service Provider Study

We are currently developing our methodology and expect that it will involve the sorts of enquires set out below.

Where will the field work be done?

Areas where we have reports of good practice (ie some services provided will be studied, standards analysed and unmet needs identified).

Line of enquiry

Areas of enquiry will include:

- Referral process
- Coordination with other services
- Palliative care specialist support availability
- Staff and training levels
- Cultural appropriateness
- Implementation of cultural protocols in service delivery
- Symptom management
- Physical needs
- Counselling and or grief/loss issues
- Funeral issues

The study will investigate how services compare with Palliative Care Australia (PCA) standards and enquire into the appropriateness of PCA standards from the viewpoint of the service provider and the community it serves.

Some studies might also examine 'Good Practice' in planning for or developing protocols for the delivery of palliative care services to Indigenous clients.

Outcomes will include:

- Understanding how the service model works
- Documentation of good practice service models
- Review of suitability of PCA Standards

Field time

Approximately 3 days in the field, between July and September.

Approval of Methodology

Our proposed methodology will be presented for approval to the Aboriginal Health and Medical Research Council AHMRC (NSW) Ethics Committee in June 2002. We are also consulting with each of the other state level ACCHS umbrella bodies about their ethics requirements.

(Note this attachment was modified for each State to reflect the current status of ethics approval).

ATTACHMENT B1

INDIVIDUAL CONSENT FORM

Name of Project	National Palliative Care Scoping Study
Detailed brief on the project addressing: <ul style="list-style-type: none"> – Why is the information being collected – How the information will be used – Any necessary definition of terms – Timeframe for data use – How data will be disposed 	Is a brief of the research attached? Yes..... No..... Number of pages of the brief? Pages
Data Custodian and Data Repository	Kate Sullivan, Kate Sullivan and Associates Pty Ltd 22 Waterview Street Balmain NSW 2041
Right to withdraw	1. I understand that I have the right to withdraw my consent and cease any further involvement in the research project at any time and without any penalty, either financial or personal.
Purpose of the research	2. The purpose of the research, as outlined in the attached brief numbered pages 1 and 2, has been explained to me and I have had the opportunity to ask questions about the project.
Declaration	3. I have not suffered a close bereavement in the last six months
Confidentiality and Anonymity	4. I am assured that any information provided by me or relating to me or any personal details obtained in the course of this research are confidential and that my name or any identifiable information will neither be used nor published without my written permission.
Aboriginal community consent	5. I am assured that any information provided in the course of this research that identifies the Aboriginal or Torres Strait Islander community to which I belong, including de-identified data will not be used nor published without the written permission of the Aboriginal or Torres Strait Islander organisations to which it pertains.
Timeframe	6. I am assured that the Aboriginal community has agreed that an adequate time-frame to consider the appropriateness of this project has been provided.
Community consultation	7. I am assured that the Aboriginal community through its (insert name of state level ACCHS) ethics committee or directors has been duly consulted and that any required negotiation has occurred.
Data Security	8. I am assured that the information in the brief indicates: <ul style="list-style-type: none"> – Those responsible for the security of data – Those who will have access to the data – Any intended third party to who data will be disclosed – Details for data storage and destruction – A requirement for additional consent for any change in use – Provision to preclude derived information being linked to multiple or other data banks.

INDIVIDUAL CONSENT FORM *continued*

Ethical Provisions	9. I am assured that the ethical provision relating to the health of Aboriginal people, as enunciated in NACCHO, AH& MRC and NH&MRC publications, have been complied with and that there are terms of reference for any variation from these protocols.
Free and informed consent	10. I freely give my consent in the above-mentioned research project.
Contacts	<p>11. I understand that if I have any complaints or questions concerning this research project I can contact the principle researcher mentions above or the AH&MRC Ethics Committee as follows:</p> <p>The Chairperson AH&MRC Ethics Committee PO Box 1656 Telephone 96981099</p> <p>OR the (insert relevant state ACCHS Ethics committee or manger details)</p> <p>OR (insert name and contact details of researcher/s)</p>
Signed by or on behalf of Kate Sullivan and Associates Pty Ltd	
Signature	Date
Position	Witnessed by
I [print name]	hereby agree to participate in the above-mentioned research.
Signed	Date
Witnessed by	

INDIGENOUS COMMUNITY ORGANISATIONAL CONSENT FORM

Name of Project	National Palliative Care Scoping Study
Detailed brief on the project addressing: <ul style="list-style-type: none"> - Why is the information being collected - How the information will be used - Any necessary definition of terms - Timeframe for data use - How data will be disposed 	<p>Is a brief of the research attached? Yes..... No.....</p> <p>Number of pages of the brief? Pages</p>
Data Custodian	Kate Sullivan, Kate Sullivan and Associates Pty Ltd 22 Waterview Street Balmain NSW 2041
Data Repository	Kate Sullivan and Associates Pty Ltd 22 Waterview Street Balmain NSW 2041
Organisation's Right to withdraw	1. It is acknowledged that the Indigenous Service Provider or Indigenous Community Organisation has the right to withdraw its consent and cease any further involvement in the research project at any time and without any penalty, either financial or personal and without any reasons being given.
Purpose of the research	2. The purpose of the research, as outlined in the attached brief numbered pages 1 and 2 , has been explained to me and I have had the opportunity to ask questions about the project.
Client Confidentiality and Anonymity	3. The Indigenous Service Provider or Indigenous Community Organisation has been assured that any information it provides or any details of its clients obtained in the course of this research, are confidential and that clients' identity or any identifiable information will neither be used nor published without their written permission.
Aboriginal community consent	4. The Indigenous Service Provider or Indigenous Community Organisation has been assured that, unless otherwise specifically stated and agreed upon, any information provided in the course of this research that identifies the Indigenous Service Provider/ Indigenous Community Organisation or the Aboriginal or Torres Strait Islander community which it serves, including de-identified data, will not be used nor published without the written permission of the written permission of the Indigenous Service Provider or Indigenous Community Organisation to which it pertains.
Timeframe	5. The Indigenous Service Provider / Indigenous Community Organisation has been given an adequate time-frame to consider the appropriateness of this project.
Community consultation	6. The Indigenous Service Provider/Indigenous Community Organisation has been assured that the schedule for the proposed research includes provision for community consultation and negotiation has occurred to the satisfaction of this Indigenous Service Provider/Indigenous Community Organisation or, if applicable, the (<i>insert name of state level ACCHS</i>) Ethics Committee or Director.

INDIGENOUS COMMUNITY ORGANISATIONAL CONSENT FORM

Data Security	<p>7. The Indigenous Service Provider/Indigenous Community Organisation has been assured that the information in the brief indicates:</p> <ul style="list-style-type: none">– Those responsible for the security of data– Those who will have access to the data– Any intended third party to who data will be disclosed– Details for data storage and destruction– A requirement for additional consent for any change in use– Provision to preclude derived information being linked to multiple or other data banks.
Ethical Provisions	<p>8. The Indigenous Service Provider/Indigenous Community Organisation has been assured that the Ethical provision relating to the health of Aboriginal people, as enunciated in NACCHO, AH& MRC and NH&MRC publications, have been complied with and that there are terms of reference for any variation from these protocols and that the AH& MRC Ethics Committee and the (relevant State ACCHS Ethics committee or State Director) has endorsed the project.</p>
Free and informed consent	<p>9. The Indigenous Service Provider/ Indigenous Community Organisation freely gives its consent in the above-mentioned research project, subject to compliance with the conditions contained within this consent agreement.</p>
Contacts	<p>10. The Indigenous Service Provider / Indigenous Community Organisation understands that if it have any complaints or questions concerning this research project it can contact the principle researcher mentioned above or the AH&MRC Ethics Committee as follows:</p> <p>The Chairperson AH&MRC Ethics Committee PO Box 1656 Strawberry Hills NSW 2012 Telephone 96981099</p> <p>OR the (insert relevant state ACCHS Ethics committee or manager details)</p> <p>Or (name and contact details of researcher/s)</p>

INDIGENOUS COMMUNITY ORGANISATIONAL CONSENT FORM

The Indigenous Service Provider/Indigenous Community Organisation known as [insert name of organisation]

hereby authorises the above-mentioned research organisation to participate in the research and agrees, subject to the individual consent of its clients or community members, to the identified discussions and interviews and to release any relevant and required information for the purpose of this research project.

Signed by or on behalf of Kate Sullivan and Associates Pty Ltd

Signature

Date

Position

Witnessed by

Signed on behalf of the Indigenous Service Provider/Indigenous Community Organisation known as [insert name of organisation]

Signature

Date

Position

Witnessed by

ATTACHMENT B2

INFORMED CONSENT STATEMENT – INDIGENOUS PALLIATIVE CARE STUDY

I am reading this statement about the research project to you so that you can decide whether you want to take part. The research is being undertaken by Kate Sullivan and Associates Pty Ltd, and you will be interviewed by

I have handed you a standard 'consent form' which you can read and sign if you want, or you can sign a copy of this statement after I have read it. That form has the details of who you can complain to if you are unhappy about anything.

The research is designed to find out about your experience of and your views about palliative care services. Palliative care is:

- caring for people who have a sickness that can't be cured or who are sick or frail and very close to passing away, and
- providing support and information to their families and carers including after the person has passed away
- this care and support might be provided in a hospital setting (including hospice, hostel, nursing home) or at home.

The information we collect will be written up to be used by the Australian Government Department of Health and Ageing to help their planning. It will also be used by the Department to develop guidelines and teaching materials so that people delivering palliative care services (eg hospitals or clinicians or nursing homes, doctors, nurses and social workers) can deliver services in a way that is sensitive to the needs of Aboriginal and or Torres Strait Islander peoples. The Australian Government has engaged the Wodonga TAFE in partnership with the Mungabareena Aboriginal Corporation to develop these guidelines.

The information you give us will go into a report to the Australian Government. Your name will not be used in the report. If for any reason we do want to use your name or identify you in any way we will have to get special written permission from you.

If you agree to take part in the discussion group (*or interview*) you can change your mind at any time. We expect the discussion group (*interview*) to last for about one and half hours (*about one hour*). We do not think that there will be any bad outcomes for you if you take part in this research. It is my understanding that you have not suffered a close bereavement in the last six months.

Are there any questions about the project?

If you agree to take part can you sign this paper. I will ask (community witness) to sign first to say that I have read this statement to you and ask her/him to witness our signature.

Community Witness at.....date.....

Iagree to take part and I have not suffered a close bereavement with in the last six months (signature)..... .Witnessed.....

Iagree to take part and I have not suffered a close bereavement with in the last six months (signature)..... .Witnessed.....

Iagree to take part and I have not suffered a close bereavement with in the last six months (signature)..... .Witnessed.....

ATTACHMENT C

POTENTIAL FIELD WORK LOCATIONS

The locations below have been selected for potential fieldwork following national scoping, consultation with Federal, State and Territory bodies, and circulation of information about the project via a newsletter which was sent to 1,300 recipients, including all Indigenous Community Controlled Health Organisations.

	Regional Studies – needs analysis	Targeted Protocol development	Good Practice Examples, Consideration of Standards and needs identification
Target areas	Areas where little is happening or about which we know little	Areas where some services have begun and where scoping has identified protocol development as an immediate need.	Areas where we have reports of good practice (ie some services provided) – selected to cover a range of service models)
Possible areas	<p>Metropolitan Adelaide SA</p> <p>Metropolitan Sydney (Western Sydney – Mt Druitt area) NSW</p> <p>Nowra¹ – South Coast NSW</p> <p>Selected area of Brisbane region (either Ipswich Inala, Woodridge or Toowoomba) Qld</p> <p>Rockhampton (few if any services except HACC) Qld</p> <p>Cairns region (with Townsville as a satellite) Qld</p> <p>Nhulunbuy, East Arnhem Land NT</p> <p>Perth or Goldfields WA</p> <p>TSI – Thursday Island</p> <p>Tennant Creek</p> <p>Corrective Services Facility²</p>	<p>Rumbalara (Vic)</p> <p><i>This type of approach or some variation of it may come out of the partnership discussions in stage 4/5.</i></p>	<p><i>Service delivery</i></p> <p>Metropolitan Adelaide – SA</p> <p>Cross Border Area eg Nganampa Health – SA</p> <p>Wanarn or the Kimberley WA</p> <p>Tiwai Health – NT</p> <p>Mt Isa – Qld</p> <p>Booroooegen Djuen – Kempsey, NSW</p> <p><i>Planning, co-ordination or protocol development</i></p> <p>Flinders Uni/ RFDS project – and Oak Valley?</p> <p>Cairns Manual project.³</p>
Associated categories	Sub category of regional approach; to follow up previous regional study. Eg Pilbara /Kimberley This would include selected sample sites only to assess the impact of any recommendations that have been implemented.		A subcategory of good practice: Palliative care services which have Indigenous Liaison Officers or Indigenous staff. Eg Top End Palliative Care, Hume PC, Royal District Nursing Service in Adelaide?

¹ Nowra is included because it has an Aboriginal nursing home (or aged care home) and because of a Primary Health Care initiative that was undertaken there to try to encourage Aboriginal people to use GPs and to encourage GPs to provide better service to Aboriginal people. It would be interesting to see if this project (said to have been successful) has had any impact on palliative care. An alternative to Nowra would be a site on the NSW North Coast – say mid or southern network section of the Mid North Coast Area Health Service.

² given the high number of Indigenous people in prison it may be appropriate to investigate one correctional institution (high Aboriginal populations in NSW gaols are in Tamworth, Broken Hill, Grafton and Mannus) The probable location for this study would be Perth. Appropriate consent would need to be obtained.

³ This should possibly come under column two.

ATTACHMENT D 1

REGIONAL NEEDS STUDIES: INTERVIEW/DISCUSSION QUESTIONS

■ Community members – individuals and families

Before visiting each region consult with the ACCHS or other appropriate organisation or our local adviser/researcher about terminology for 'passing away' or 'finishing up' and modify as needed. Throughout interview note local terminology and match.

Remember that if a question seems redundant because of what people have said it is best to ask the question and ask the group if they think they have covered that area or if there is something they want to add – rather than assume it has been covered.

.....

Hand out copies of previous Newsletters and the Consent Form.

.....

Thank you for agreeing to be interviewed for our project. As you will be aware we are undertaking a study into Indigenous palliative care to find out what sort of services exist and to identify unmet needs.

The information we collect will be written up into a report for the Australian Government Department of Health and Ageing to help them ensure that the National Palliative Care Strategy properly takes account of Indigenous issues – to help them with their planning. The Department will also use our report to contribute to a set of Guidelines for Palliative Care Service Providers and some associated training materials which are being developed by the Wodonga TAFE and Mungabareena Aboriginal Corporation team.

.....

Please ask the participant/s to read and sign the informed consent form and/ or read the 'statement of informed consent' and have the community witness sign it and witness signatures.

.....

I'm going to start with some questions that explore what sort of services exist in the area and what you think of them. We are interested in services for people and their families where a person is very sick and may be close to passing away and is not going to get better. The doctor and/or the healer have said there is no cure. We know this is a difficult area to talk about and we really appreciate you helping with the research. You don't have to answer any of the questions if you don't want to. Also remember there are no 'right' or 'wrong' answers. You do not have to agree with what other people say. We want to know what you all think.

1. Could we begin by you telling me your name and a bit about yourself and your family?
2. In general, how do families cope if someone is sick and maybe close to passing away and the doctors and/or the healer have said that they are not going to get better: there is no cure and nothing they can do? Do these families have enough help? Tell me what happens at the moment. Who helps? What do they do? (prompt list: information, transport, pain management, equipment, counselling.)
- 2a Are there times when people need help but they don't get help? What happens then?
3. The sort of services we are interested in finding out about are called 'palliative care' services. These services might be delivered at home, or in a nursing home or in a hospital. They might include special equipment or special medicine for pain or comfort. Palliative Care might be given by a number of people working together – like a doctor, a nurse, health worker and a social worker. It might be counselling or support for the family or carer. Palliative Care services also include help for the family after someone has passed on.

.....

Have definition of Palliative Care handy and pass out if appropriate.

.....

In some places there are services like this, but not everywhere. We are trying to find out where they do have these services. Do you know of any services like these in your area? Which services are these? (Prompt: type of service, mainstream or Indigenous) How do you know about the services? How did you or your family find out about it?

4. Have you or your friends or family ever used any of these services? Which ones? What was the experience like? Did it work OK or were there problems?
5. Do people have to pay for these services? If they do can they claim it back from Medicare – or a private health fund? Which?
6. How you think they [*service provider/s mentioned in answer to 2 above, and target service provider*] went about doing things for, [Kooris, Murris, Anangu (etc as appropriate)]. Do you think things were done the right way? Can you give some examples? Can you tell me about something that went the right way? (Explore this question in relation to both the earlier course of the illness and also during the ‘terminal’ phase, that is close to when the person passed away, and after the person had passed away.)
7. What was the best or most useful thing the services did for your family or friends?
8. Have you heard about any times when the type of service we have been talking about (palliative care) could help here in
9. If there were a mainstream service here (one that is supposed to be for everyone – not just for Aboriginal or Torres Strait Islander people), do you think that you or other community members would use it? Why? /Why not?
10. If not, what sort of things would a mainstream service need to have, or how would it need to be so it would be used by community members? What would it take for you to want to use a mainstream palliative care service?
11. Sometimes, in some places, people pass away at home, sometimes it happens in a hospital or sometimes the clinic. Where do you think is the right place for a person to pass away? Are the problems getting that to happen?
12. When people pass away in a place like a hospital do you think there are things that the hospital or the nurses could do to make it easier for their family/relations to do the right cultural things? (*Prompts: number of visitors, visiting times, the sort of food they can bring, accommodation and food for visitors, the amount of noise visitors can make?*)
13. What do you think of the idea of Palliative Care? Is it a good idea? / Do you have any worries about palliative care?
14. What sort of information do you think people need about Palliative Care? Is there information that would have been helpful to you?
15. One of the services that is sometimes offered, or is arranged for by palliative care workers is counselling. Does something like this happen here? Have you used this sort of service? Did talking help? Is there a right way to do this, a good way for [Kooris, Murris, Anangu (etc as appropriate)] to talk with people about their grief and loss? Is there such a service available in your community – or is this handled more traditionally?
16. In some places there are issues or problems with funerals. Do people sometimes need help with things like (transporting the deceased person, cost of funeral etc) ...who helps? What sort of help is the best? What about problems or worries around funerals?
17. This is about the end of our questions. Is there anything that you want to tell us that we haven't asked about? Is there anything you want to add? Is there anyone else we should speak to.

REGIONAL NEEDS STUDIES: INTERVIEW/DISCUSSION QUESTIONS

■ Service Providers

.....

Hand out copies of consent form and copies of our last two Newsletters.

.....

Thank you for agreeing to be interviewed for our project. As you will be aware, we are undertaking a study into Indigenous palliative care to find out what sort of services exist and to identify unmet needs.

The information we collect will be written up into a report for the Australian Government Department of Health and Ageing to help them ensure that the National Palliative Care Strategy can properly take account of Indigenous issues. The Australian Government Department of Health and Ageing will also use our report to contribute to a set of Guidelines for Palliative Care Service Providers and some associated training materials which are being developed.

.....

Please ask the participants/s to read and sign the informed consent form.

Ask if there are any questions about the project.

.....

1. Can you tell me about your service?
(Prompts:
 - a) What does your service do?
 - b) Geographic coverage
 - c) Who runs it, staff management – interdisciplinary team?
2. Would you describe your service as either
 - a) a Palliative Care Service or
 - b) a service provider which provides some palliative care services or
 - c) a service which coordinates palliative care services or facilitates access to palliative care service.
 - d) other
3. What aspects of palliative care do you provide or facilitate? What services? [Leave open to them to describe and code checklist 'A' after interview]
4. Do your clients have to pay for the service? If so can they reclaim it from Medicare or a private insurer? (Which?)
5. Is the service Mainstream or Indigenous-specific?

If Mainstream ask questions 4 and 5. If Indigenous-specific go on to 6

6. Do you record the Indigenous status of your clients (eg do you record if they identify as an Aboriginal person, or a Torres Strait Islander or both an Aboriginal person and a Torres Strait Islander?)
 - a) Yes / No
 - b) If yes. How is this question administered?
 - i. Is each client asked the question? *(please tick)* **OR**
 - ii. Is the answer assumed or guessed? *(please tick)*
7. Do you know how many Aboriginal or Torres Strait Islander clients accessed your services in the last financial year? Yes / No How many?
8. Do you think that there are Indigenous clients in the area who are not accessing your services ?
Why do you think that this is?

If the service has no Indigenous clients go to question 11

9. How (and by whom) are Indigenous clients referred to your service?
10. What sort of **assessment tools** do you use to determine that Indigenous clients are palliative care clients and what their needs are?
 - 10a Does the assessment include the family or only the client?
 - 10b Do you sometimes refer people on? To whom? How does this happen?
11. Tell me about your **relationship with other Service Providers in your area?** (*Prompts: which ones, what sort of services do they provide and are they mainstream or Indigenous-specific services?*)
 - 11a Can you give me an example of where things work well (with other service providers) and why?
 - 11b and an example of things that could be improved?
12. What sort of palliative care specialist support or expert consultation is available to you and your staff?
 - a) How important is this?
 - b) How often and in what circumstances do you use this support?
13. I just want to check with you – you might have covered this – do you offer bereavement services – describe? – or how is bereavement dealt with by Indigenous clients?
14. Do you have any regular contacts with the local Aboriginal or Torres Strait Islander communities or organisations? What form has this contact taken? Have you made contact with the Aboriginal Liaison Officer in your local hospital/s?
15. Do you have any comments about the level of, or need for training? (Prompt: palliative care training or cross cultural training).
16. What sort of information is available to Indigenous people about palliative care and what gaps are there?
17. We have nearly finished now – is there anything you want to add about Indigenous Palliative Care – anything about future needs or issues?
18. Is there anyone else we should talk with in the region?

Statistics

Now I just want to get some statistics – you might need to go to your office or ask someone to help with these – we are happy to wait.

19. What are your hours/days of opening?
20. Does your service have any Indigenous staff? If yes fill in details :

Number of staff	Male staff		Female staff	
	Indigenous	Non - Ind	Indigenous	Non - Ind
Management:				
Admin:				
Doctor:				
Nursing:				
Health Worker:				
Advocate:				
Community Liaison:				
Driver:				
Volunteers				
Other				

21. Levels of training:
- a. Number of Staff with Cross Cultural Training:
 - b. Number of Staff with Palliative Care Training:
What sort of palliative care training?.....
 - c. Number of Staff with Indigenous Palliative Care Training:.....
22. Indigenous client numbers if relevant?
- a. Number of palliative care clients? Total (Fin Year) 2000/2001 patients:.....
% Aboriginal and Torres Strait Islander:.....
% Aboriginal:.....
% Torres Strait Islander:.....

% Indigenous PC clients by age	% Non-Indigenous PC clients by age
0 – 10:	0 – 10:
11 – 20	11 – 20
21 – 30	21 – 30
31 – 40	31 – 40
41 – 50	41 – 50
51 – 60	51 – 60
61 – 70	61 – 70
71 – 80	71 – 80
80+	80+

- b. Total current Indigenous patients:.....

23. Source of palliative care funding

Percentage	Type of funding (AHCA, HACC, Flexible, Multipurpose etc)
Australian Government Health:	
State Government:	
Local Government:	
AMS:	
ATSIC:	
Community:	
Church:	
Charity/Not For Profit:	
User Pays:	
Other:	

24. Level of Palliative Care Funding (Annual Budget)\$: If these questions do not fit your situation please describe your funding arrangements on a separate sheet.)

25. Information about respondent

- a. In Relation to working in palliative care would you describe yourself as:
 Very experienced Somewhat experienced Relatively new /inexperienced

- b. What about working with Aboriginal and Torres Strait Islander palliative care clients?
 Very experienced Somewhat experienced Relatively new / inexperienced
- c. Do you identify as an:
 Aboriginal person
 Torres Strait Islander
 Aboriginal & Torres Strait Islander person
 Non – Indigenous Person

ATTACHMENT 'A'

What services do you provide?

- Hospital
- Clinic
- Hostel
- Hospice
- Nursing Home
- Bereavement/Grief Counselling
- Advocacy
- Transport
- Funeral Services
- Funeral Funds
- Pain Management
- Disease Specific Medical (.....)
- Respite Care
- Housekeeping/home help
- Carer Support
- Voluntary Carer Arrangements
- Facilitates access to traditional medicine
- Facilitates access to traditional law and spiritual support
- Facilitates traditional mourning and/ or cleansing practices
- HACC workers
- Community Aged Care Packages
- Aboriginal Medical Service
- Service Provider Network
- Network/Support Group
- Other (.....)

REGIONAL NEEDS STUDIES: INTERVIEW/DISCUSSION QUESTIONS

■ Regional Needs: Community Organisations (not usually ACCHSs)

.....
Hand around copies of our last two newsletters and the Consent Form

.....
Thank you for agreeing to be interviewed for our project. As you will be aware we are undertaking a study into Indigenous palliative care to find out what sort of services exist and to identify unmet needs.

The information we collect will be written up into a report for the Australian Government Department of Health and Ageing to help them ensure that the National Palliative Care Strategy properly takes account of Indigenous issues. The Australian Government Department of Health and Ageing will also use our report to contribute to a set of Guidelines for Palliative Care Service Providers and some associated training materials which are being developed for them by Wodonga TAFE and Mungabareena Aboriginal Corporation.

.....
Please ask the participants/s to read and sign the informed consent form

-
1. How do families cope if someone is sick and maybe close to passing away and the doctors and/or the healer have said that they are not going to get better; there is no cure and nothing they can do to save their life? Do these families have enough help? What sort of assistance would they need that they might not be getting? (*Prompt list: – Information, transport, pain management, equipment, counselling.*)
 2. The sort of services we are interested in finding out about are called ‘palliative care’ services. These services might be delivered at home, or in a nursing home or in a hospital. They might include special equipment or special medicine for pain or comfort. Palliative Care might be given by a number of people working together – like a doctor, a nurse, Aboriginal health worker, Aboriginal Liaison worker and a social worker. It might be counselling or support for the family or carer/s. Palliative Care services also include help for the family after someone has passed on.

In some places there are palliative care services but not everywhere. We are trying to find out where they exist? Do you know of any services like these in your area? Which services are these? What do they do? (*Prompt: type of service, mainstream or Indigenous*) How do you know about the Services? How did you find out about it? How do other members of the community find out?
 3. Do clients have to pay for these services? Who pays? If they have to pay can they claim the money back from Medicare? From private health insurance?
 4. Are the services provided by [service provider/s mentioned in answer to 2 above, or the target ‘good service provider] the right sort of services for Aboriginal or Torres Strait Islander people? How you think they went/go about doing things for, [Kooris, Murris, Anangu (etc as appropriate)]: Do you think things are done the right way?
 5. Do local people use mainstream palliative care services here (if they exist) or if there were mainstream palliative care services here do you think that you or other community members would use them? Why?/Why not? If not, what sort of things would a mainstream service need to have for community members to use it? What would it take to make you want to use a mainstream palliative care service?
 6. What do you think the main issues are for Aboriginal (or Torres Strait Islander) people who need palliative care?

7. Sometimes, in some places, people pass away at home, sometimes it happens in a hospital or sometimes the clinic. Where do you think is the right place for a person to pass away? Are the problems getting that to happen?
8. When people pass away in a place like a hospital do you think there are things that the hospital or the nurses could do to make it easier for their family/relations to do the right cultural things? (*Prompts: number of visitors, visiting times, the sort of food they can bring, accommodation and food for visitors, the amount of noise visitors can make?*)
9. What information is available to people about palliative care? What gaps are there?
10. We would appreciate any information about traditional practices (in relation to palliative care) that you feel comfortable sharing with us. We are asking for this information to assist us to identify appropriate ways that these practices can be better supported, and ways that local service providers could be encouraged to incorporate or facilitate access to them where individuals or the community would like this to happen. Do you know of any specific cultural practices which would help the clients and family through this difficult time. For example, sorry business /funeral practices as well as healing.
11. We are nearly finished now. Is there anything else you think we should know about or that you want to add about palliative care?
12. Is there anyone we should be talking to?

ATTACHMENT D2

GOOD PRACTICE STUDIES: INTERVIEW/DISCUSSION QUESTIONS

■ Community and individuals

These questions or variations of them will be asked by or in the company of a local researcher or adviser. Before the interview or focus group, go through the questions with the local researcher or adviser and modify the form of words to suit the location.

Remember that if a question seems redundant because of what people have said it is best to ask the question and ask the group if they think they have covered that area or if there is something they want to add – rather than assume it has been covered.

.....

Hand out copies of previous Newsletters and the Consent Form.

.....

Thank you for agreeing to be interviewed for our project. As you will be aware we are undertaking a study into Indigenous palliative care to find out what sort of services exist and to identify unmet needs.

The information we collect will be written up into a report for the Australian Government Department of Health and Ageing to help them ensure that the National Palliative Care Strategy properly take account of Indigenous issues – to help them with their planning. The Department will also use our report to contribute to a set of Guidelines for Palliative Care Service Providers and some associated training materials which are being developed by the Wodonga TAFE and Mungabareena Aboriginal Corporation team.

Please ask the participants/s to read and sign the informed consent form and/or read the ‘statement of informed consent’ and have the community witness sign it and witness signatures.

The area we are going to ask question about is a difficult area for many people. Please do not feel that you have to answer any of the questions if you don't want to. Also remember there are no ‘right’ or ‘wrong’ answers. You do not have to agree with what other people say. We want to know what you all think.

1. Could we begin by you telling me your name and a bit about yourself and your family?
2. If some one is very sick and close to passing away and the doctor and /or the healer says that they won't get better and there is no cure for the sickness, how are these people cared for? Who looks after them? What sort of help do they get?
3. When some one is sick like this and won't get better, what are the sorts of problems that happen? What needs to be done about these problems?
4. Who do they/you get help from? [*Prompt: Clinic, CCHO, traditional healers, hospital, palliative care SP HACC workers?*] What sort of help does the sick person or family get from these sorts of services?
 - a. How do people know about these services?
 - b. If no one has mentioned the service provider/s which is the subject of the study ask ‘What about theservice? Has anyone had help from them? What sorts of things do they do?’
5. What are some of the good things that the [name the service provider/s mentioned in answer to 2 above and the ‘target’ service provider] does to help the family and the sick person?
6. Do people have to pay for these services? If they do, can they claim it back from Medicare – or a private health fund? Which?

7. How do you think they [service provider/s mentioned in answer to 2 above, and 'target' service provider] went about doing things for, [Kooris, Murris, Anangu (etc as appropriate)]. Do you think things were done in the right way? Can you give some examples? Can you tell me about something that went the right way? (Explore this question in relation to: the earlier course of the illness and also during the 'terminal' phase – close to when the person passed away, and after the person had passed away.)
8. What about when a person is very close to finishing up or passing away? Who helps then? Are there sometimes problems?
9. Sometimes, in some places, people pass away at home, sometimes it happens in the hospital, sometimes in the clinic. Where do you think is the right place for people to pass away? Are there problems in getting that to happen?

If it isn't going to upset you can you tell me about time when someone passed away in the right place, and when it was a good thing. What happened then? (If there are examples ask people if the outcome was OK or not)

10. When people pass away in a place like a hospital do you think there are things that the hospital or the nurses could do to make it easier for their family/relations to do the right cultural things? (*Prompts: number of visitors, visiting times, the sort of food they can bring, accommodation and food for visitors, the amount of noise visitors can make?*)
11. What do you think about the idea of palliative care? Do you think it is a good thing for people who can't get well? – (Explain what is meant by the term (have copies of the definition handy) Did you hear about palliative care before this research? Do you have any worries about the idea of palliative care?.
12. What sort of information do you think people need about palliative care? Is there information that would have been helpful to you?
13. One of the services that is sometimes offered or arranged by palliative care workers is counselling. Does something like this happen here? Have you used this sort of service? Did talking help? Is there a right way to do this, a good way for [Kooris, Murris, Anangu (etc as appropriate)] to talk with people about their grief and loss? Is there such a service available in your community? How does it work here? Who helps people with sadness and sorry feelings?
14. In some places there are issues or concerns about funerals for various reasons. Do people sometimes need help with things like (transporting the deceased person, cost of funeral etc)? Who helps? What sort of help is the best? What about problems or worries around funerals? (Only ask if this issue has not come up already!!)
15. This is about the end of our questions. Is there anything that you want to tell us that we haven't asked about? Is there anything else you want to add? Is there anyone else we should speak to?

GOOD PRACTICE STUDIES: INTERVIEW/DISCUSSION QUESTIONS

■ Service Providers

.....

Hand out copies of previous Newsletters and the Consent Form.

.....

Thank you for agreeing to be interviewed for our project. As you will be aware we are undertaking a study into Indigenous palliative care to find out what sort of services exist and to identify unmet needs.

The information we collect will be written up into a report for the Australian Government Department of Health and Ageing to help them ensure that the National Palliative Care Strategy properly takes account of Indigenous issues. The Australian Government Department of Health and Ageing will also use our report to contribute to a set of Guidelines for Palliative Care Service Providers and some associated training materials which are being developed.

.....

Please ask the participants/s to read and sign the informed consent form

.....

1. Can you tell me about your service (*Prompts: History, why decided it was needed, philosophy etc, geographic coverage*)
 - Who runs it, staff, management – interdisciplinary team?
 - What does your service do? Who funds it?
2. Is the service mainstream or Indigenous-specific?

If mainstream ask questions 3 and 4. If Indigenous-specific go on to question 5.

3. Do you record the Indigenous status of your clients (eg do you record if they identify as an Aboriginal person, or a Torres Strait Islander or both an Aboriginal person and a Torres Strait Islander?)
 - a. Yes / No
 - b. If yes. How is this question administered?
 - i. Is each client asked the question? (please tick) OR
 - ii. Is the answer assumed or guessed? (please tick)
4. Would you describe your service as either
 - a) a Palliative Care Service, or
 - b) a service provider which provides some palliative care services, or
 - c) a service which coordinates palliative care services or facilitates access to palliative care services?
 - d) Other
5. What aspects of palliative care do you provide or facilitate? What services?
[Leave open to them to describe and code checklist 'A' later – after interview]
6. Do your clients have to pay for the service? If so can they reclaim it from Medicare or a private insurer? (Which?)

7. What aspects of your palliative care service do you consider **works very well** and why?
Tell me the one thing that is best or most significant about your service?
7a Any other things that work well?
8. If there was **one** thing about your service that could be improved on – what would it be and why?
8a Any other things that could be improved on?
9. How (and by whom) are clients **referred** to your service?
10. What sort of **assessment tools** do you use to determine that they are palliative care clients and what their needs are?
10a Does the assessment include the family or only the client?
10b Do you sometimes refer people on? To whom? How does that happen?
11. Tell me about your **relationship with other Service Providers**?
(Prompts: *which ones, what sort of services do they provide and are they mainstream or indigenous-specific services?*)
11a Can you give me an example of where things work well (with other service providers) and why?
And an example of things that could be improved?
12. Are there barriers to Aboriginal or Torres Strait Islander people accessing palliative care services?
What do you think they are? What do you think could be done about them?
13. What sort of information is available to Indigenous people about palliative care and what gaps are there?
14. Do you have any comments about the level of, or need for training?
(Prompt: *palliative care training or cross cultural training*)
15. What sort of palliative care specialist support or expert consultation is available to you and your staff?
a) How important is this?
b) How often and in what circumstances do you use this support?
16. You might have covered this already – Do you offer bereavement services – describe? –
or – How is bereavement dealt with by Indigenous clients?
17. What sort of contact does your organisation have with the Aboriginal community and in particular with:
a) ACCHS (if not an ACCHS)
b) Aboriginal Liaison Officer at hospital,
c) Community organisations (which ones?)
d) Other
18. There has been a lot of talk about standards in palliative care lately. What do you think makes a good palliative care service? What would you say are the 3-5 most critical things?
19. Are you familiar with the Palliative Care Australia (PCA) Standards? (*Have a copy available to give them*)
Yes or No?
If yes ask: Do you consider the PCA standards are relevant for services that are delivered to Indigenous clients? Is there any thing you would add, remove or change? *If they are not familiar with them – don't pursue the question.*
20. Do you have any comments on the level or nature of palliative care training of staff in your service or the nature and availability of palliative care training?
21. That is nearly the end of my questions except for some statistical information. Is there any thing you would like to add about what you consider are the unmet needs in Indigenous palliative care, or about how families cope when someone is sick and is not going to get better, or after someone passes away after such an illness? (*Do they have enough help? What sort of assistance do they need that they might not be getting?*)

Statistics

Now I just want to get some statistics.

22. What are your hours/days of opening?

23. Client Numbers

a. Number of palliative care clients?

Total (Fin Year) 2000/2001 patients:

% Aboriginal and Torres Strait Islander:

% Aboriginal:

% Torres Strait Islander:

% Indigenous PC clients by age	% Non-Indigenous PC clients by age
0 – 10:	0 – 10:
11 – 20	11 – 20
21 – 30	21 – 30
31 – 40	31 – 40
41 – 50	41 – 50
51 – 60	51 – 60
61 – 70	61 – 70
71 – 80	71 – 80
80+	80+

b. Total current Indigenous patients:.....

24. Staff

Number of staff	Male staff		Female staff	
	Indigenous	Non - Ind	Indigenous	Non - Ind
Management:				
Admin:				
Doctor:				
Nursing:				
Health Worker:				
Advocate:				
Community Liaison:				
Driver:				
Volunteers				
Other				

25. Levels of training:
- a. Number of Staff with Cross Cultural Training:
 - b. Number of Staff with Palliative Care Training:
What sort of palliative care training?
 - c. Number of Staff with Indigenous Palliative Care Training:

26. Source of palliative care funding:

Percentage	Type of funding (AHCA, HACC, Flexible, Multipurpose etc)
Australian Government Health:	
State Government:	
Local Government:	
AMS:	
ATSIC:	
Community:	
Church:	
Charity/Not For Profit:	
User Pays:	
Other:	

Level of Palliative Care Funding (Annual Budget)\$:

If these questions do not fit your situation please describe your funding arrangements on a separate sheet.)

27. Information about respondent

- a. In relation to working in palliative care would you describe yourself as:
 - Very experienced Somewhat experienced Relatively new/inexperienced
- b. What about working with Aboriginal and Torres Strait Islander palliative care clients?
 - Very experienced Somewhat experienced Relatively new/inexperienced
- c. Do you identify as an:
 - Aboriginal person
 - Torres Strait Islander
 - Aboriginal & Torres Strait Islander person
 - Non-Indigenous Person

ATTACHMENT 'A'

What services do you provide?

- Hospital
- Clinic
- Hostel
- Hospice
- Nursing Home
- Bereavement/Grief Counselling
- Advocacy
- Transport
- Funeral Services
- Funeral Funds
- Pain Management
- Disease Specific Medical (.....)
- Respite Care
- Housekeeping/home help
- Carer Support
- Voluntary Carer Arrangements
- Facilitates access to traditional medicine
- Facilitates access to traditional law and spiritual support
- Facilitates traditional mourning and/ or cleansing practices
- HACC workers
- Community Aged Care Packages
- Aboriginal Medical Service
- Service Provider Network
- Network/Support Group
- Other (.....)

GOOD PRACTICE STUDIES: INTERVIEW/DISCUSSION QUESTIONS

■ Community Organisations (not usually ACCHSs)

.....

Hand out copies of previous Newsletters and the Consent Form.

.....

Thank you for agreeing to be interviewed for our project. As you will be aware we are undertaking a study into Indigenous palliative care to find out what sort of services exist and to identify unmet needs.

The information we collect will be written up into a report for the Australian Government Department of Health and Ageing to help them ensure that the National Palliative Care Strategy properly takes account of Indigenous issues. The Australian Government Department of Health and Ageing will also use our report to contribute to a set of Guidelines for Palliative Care Service Providers and some associated training materials which are being developed for them by Wodonga TAFE and Mungabareena Aboriginal Corporation.

.....

Please ask the participants/s to read and sign the informed consent form

.....

1. How do families cope if someone is sick and maybe close to passing away and the doctors and/or the healer have said that they are not going to get better; there is no cure and nothing they can do to save their life? Do these families have enough help? What sort of assistance would they need that they might not be getting? (*Prompt list: – Information, transport, pain management, equipment, counselling.*)
2. The sort of services we are interested in finding out about are called ‘palliative care’ services. These services might be delivered at home, or in a nursing home or in a hospital. They might include special equipment or special medicine for pain or comfort. Palliative Care might be given by a number of people working together – like a doctor, a nurse, Aboriginal health worker, Aboriginal Liaison worker and a social worker. It might be counselling or support for the family or carer/s. Palliative Care services also include help for the family after someone has passed on.

In some places there are palliative care services but not everywhere. We are trying to find out where they exist? Do you know of any services like these in your area? Which services are these? What do they do? (*Prompt: type of service, mainstream or Indigenous*) How do you know about the Services? How did you find out about it? How do other members of the community find out?
3. Do clients have to pay for these services? Who pays? If they have to pay can they claim the money back from Medicare? From private health insurance?
4. Are the services provided by [service provider/s mentioned in answer to 2 above, or the target ‘good service provider’] the right sort of services for Aboriginal or Torres Strait Islander people? How you think they went/go about doing things for, [Kooris, Murris, Anangu (etc as appropriate)]? Do you think things are done the right way?
5. Do local people use mainstream palliative care services here (if they exist) or if there were mainstream palliative care services here do you think that you or other community members would use them? Why?/Why not? If not, what sort of things would a mainstream service need to have for community members to use it? What would it take to make you want to use a mainstream palliative care service?

6. What do you think the main issues are for Aboriginal (or Torres Strait Islander) people who need palliative care?
7. Sometimes, in some places, people pass away at home, sometimes it happens in a hospital or sometimes the clinic. Where do you think is the right place for a person to pass away? Are the problems getting that to happen?
8. When people pass away in a place like a hospital do you think there are things that the hospital or the nurses could do to make it easier for their family/relations to do the right cultural things? (*Prompts: number of visitors, visiting times, the sort of food they can bring, accommodation and food for visitors, the amount of noise visitors can make?*)
9. What information is available to people about palliative care? What gaps are there?
10. We would appreciate any information about traditional practices (in relation to palliative care) that you feel comfortable sharing with us. We are asking for this information to assist us to identify appropriate ways that these practices can be better supported, and ways that local service providers could be encouraged to incorporate or facilitate access to them where individuals or the community would like this to happen. Do you know of any specific cultural practices which would help the clients and family through this difficult time. For example, sorry business/ funeral practices as well as healing.
11. We are nearly finished now. Is there anything else you think we should know about or that you want to add about palliative care?
12. Is there anyone we should be talking to?

ATTACHMENT D3

QUESTIONS POSTED TO SELECTED SERVICE PROVIDERS AND COMMUNITY ORGANISATIONS

- **Community Organisations who we cannot visit but who have either responded to our Newsletter or the Mainstream questionnaire or whom we have been referred to**

Dear

Thank you for responding to our Newsletter or to our earlier enquiry about Palliative Care Services for Indigenous clients. Our project is going very well and we are now in our field work stage. See Newsletter No 2 enclosed.

We have not been able to visit all of the places which we would have liked and so we have decided to contact some of the organisations which we feel have a lot to offer our study but which it is not possible for us to visit.

I have attached a set of questions which we would appreciate your answering for us. You could do this either by writing the answers and posting, faxing or emailing them to us, or you may prefer you could call us on our 1800 810 234 and we will be happy to speak with you about your responses.

Before you answer the questions you should read and complete the Informed Consent Form which has a project description attached to it. Can you please return this to us along with your answers to the questions. If you do not want to take part in this research you can phone us on the 1800 810 234 to say so – or send us a fax.

We look forward to hearing from you soon.

Sincerely
Kate Sullivan

QUESTION SHEET

■ Community Organisations (not usually ACCHSs) V3

Please read and sign the attached *Informed Consent Form* before completing this question sheet.

Thank you for agreeing to be interviewed for our project. As you will be aware we are undertaking a study into Indigenous palliative care to find out what sort of services exist and to identify unmet needs.

The information we collect will be written up into a report for the Australian Government Department of Health and Ageing to help them ensure that the National Strategy into Indigenous Palliative care properly takes account of Indigenous issues. The Australian Government Department of Health and Ageing will also use our report to contribute to a set of Guidelines for Palliative Care Service Providers and some associated training materials which are being developed for them by Wodonga TAFE and Mungabareena Aboriginal Corporation.

Organisation Name: _____	Demographic: <input type="checkbox"/> Indigenous <input type="checkbox"/> Mainstream
Branch/Section: _____	Loc Type: <input type="checkbox"/> urban <input type="checkbox"/> rural <input type="checkbox"/> remote
Address: _____ _____	Contact Details: _____
City: _____	Title: First Name: _____
State: _____ Post Code: _____	Last Name: _____
Post Address Details _____	Position: _____
Address: _____ _____	Phone: _____
City: _____	Fax: _____
State: _____ Post Code: _____	Email: _____
_____	<i>Please use a separate sheet if necessary.</i>

Kate Sullivan & Associates
22 Waterview Street
Balmain, NSW 2041
email – project@telapacific.com.au
Phone – 02 9810 5755
Free Phone – 1800 810 234
Fax – 02 9818 4528

1. How do families cope if someone is sick and maybe close to passing away and the doctors and/or the healer have said that they are not going to get better – there is no cure and nothing they can do to save their life? Do these families have enough help? What sort of assistance would they need that they might not be getting?
2. The sort of services we are interested in finding out about are called ‘palliative care’ services. These services might be delivered at home, or in a nursing home or in a hospital. They might include special equipment or special medicine for pain or comfort. Palliative care might be delivered by a number of people working together – like a doctor, a nurse, Aboriginal health worker, Aboriginal Liaison worker and a social worker. It might be counselling or support for the family or carer/s. Palliative Care services also include help for the family after someone has passed on.

In some places there are palliative care services but not everywhere. We are trying to find out where they exist? What services exist in your area and what do they do? *(Please include: type of service and whether mainstream or Indigenous)*

- 2a How do you know about the Services? How did you find out about it? How do other members of the community find out?
3. Who pays for these services? Do clients have to pay for these services? – If they have to pay can they claim the money back from Medicare? From Private Health Insurance?
4. Are the services provided the right sort of services for Aboriginal or Torres Strait Islander people? How you think they went/go about doing things for aboriginal or Torres Strait Islander people? Do you think things are done the right way?
5. Do local people use mainstream palliative care services here (if they exist) or if there were mainstream palliative care services here do you think that you or other community members would use them? Why? /Why not? If not – What sort of things would a mainstream service need to have for community members to use it? What would it take to make you want to use a mainstream palliative care service?
6. What do you think the main issues are for Aboriginal (or Torres Strait Islander) people who need Palliative Care?
7. What information is available to Aboriginal or Torres Strait Islander people in your area about palliative care? What gaps are there?
8. We would appreciate any information about traditional practices (in relation to palliative care) that you feel comfortable sharing with us. We are asking for this information to assist us to identify appropriate ways that these practices can be better supported, and ways that local service providers could be encouraged to incorporate or facilitate access to them where individuals or the community would like this to happen. Do you know of any specific cultural practices which would help the clients and family through this difficult time. For eg sorry business /funeral practices as well as healing.
9. Is there anything else you think we should know about or that you want to add about palliative care? Is there anyone we should be talking to?

QUESTIONS POSTED

- Questions to be posted Palliative Care Service Providers who we cannot visit but who have either responded to our Newsletter or the Mainstream questionnaire or whom we have been referred to

Dear

Thank you for responding to our Newsletter or to our earlier enquiry about Palliative Care Services for Indigenous clients. Our project is going very well and we are now in our field work stage. See Newsletter No 2 enclosed.

We have not been able to visit all of the places which we would have liked and so we have decided to contact some of the organisations which we feel have a lot to offer our study but which it is not possible for us to visit.

I have attached a set of questions which we would appreciate your answering for us. You could do this either by writing the answers and posting, faxing or emailing them to us, or you may prefer you could call us on our 1800 810 234 and we will be happy to speak with you about your responses.

Before you answer the questions you should read and complete the Informed Consent Form which has a project description attached to it. Can you please return this to us along with your answers to the questions. If you do not want to take part in this research you can phone us on the 1800 810 234 to say so – or send us a fax.

We look forward to hearing from you soon.

Sincerely

Kate Sullivan

QUESTION SHEET

■ Palliative Care Service Provider – Needs

Please read and sign the attached *Informed Consent Form* before completing this question sheet.

Thank you for agreeing to be interviewed for our project. As you will be aware we are undertaking a study into Indigenous palliative care to find out what sort of services exist and to identify unmet needs.

The information we collect will be written up into a report for the Australian Government Department of Health and Ageing to help them ensure that the National Strategy into Indigenous Palliative care properly takes account of Indigenous issues. The Australian Government Department of Health and Ageing will also use our report to contribute to a set of Guidelines for Palliative Care Service Providers and some associated training materials which are being developed for them by Wodonga TAFE and Mungabareena Aboriginal Corporation.

Organisation Name: _____	Demographic: <input type="checkbox"/> Indigenous <input type="checkbox"/> Mainstream
Branch/Section: _____	Loc Type: <input type="checkbox"/> urban <input type="checkbox"/> rural <input type="checkbox"/> remote
Address: _____ _____	Contact Details: _____
City: _____	Title: _____ First Name: _____
State: _____ Post Code: _____	Last Name: _____
Post Address Details _____	Position: _____
Address: _____ _____	Phone: _____
City: _____	Fax: _____
State: _____ Post Code: _____	Email: _____

Please use a separate sheet if necessary.

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22 Waterview Street
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1. Can you tell me about your service? Please cover the following:
 - History, why decided it was needed, philosophy, geographic coverage
 - Who runs it, staff, management – interdisciplinary team?
 - What does your service do? Who funds it?

2. Is the service Mainstream or Indigenous specific?
 If Mainstream please answer questions 3 and 4. If Indigenous specific go on to 5

3. Do you record the Indigenous status of your clients (eg do you record if they identify as an Aboriginal person, or a Torres Strait Islander or both an Aboriginal person and a Torres Strait Islander)?
 - a. Yes / No
 - b. If yes. How is this question administered?
 - i. Is each client asked the question? *(please tick)* **OR**
 - ii. Is the answer assumed or guessed? *(please tick)*

4. Would you describe your service as either
 - a) a Palliative Care Service or
 - b) a service provider which provides some palliative care services or
 - c) a service which co-ordinates palliative care services or facilitates access to palliative care service.
 - d) other

5. What aspects of palliative care do you provide or facilitate? What services?

<input type="checkbox"/> Hospital <input type="checkbox"/> Clinic <input type="checkbox"/> Hostel <input type="checkbox"/> Hospice <input type="checkbox"/> Nursing Home <input type="checkbox"/> Bereavement/Grief Counselling <input type="checkbox"/> Advocacy <input type="checkbox"/> Transport <input type="checkbox"/> Funeral Services <input type="checkbox"/> Funeral Funds <input type="checkbox"/> Pain Management <input type="checkbox"/> Disease Specific Medical (.....) <input type="checkbox"/> Respite Care <input type="checkbox"/> Housekeeping/home help <input type="checkbox"/> Carer Support	<input type="checkbox"/> Voluntary Carer Arrangements <input type="checkbox"/> Facilitates access to traditional medicine <input type="checkbox"/> Facilitates access to traditional law and spiritual support <input type="checkbox"/> Facilitates traditional mourning and/or cleansing practices <input type="checkbox"/> HACC workers <input type="checkbox"/> Community Aged Care Packages <input type="checkbox"/> Aboriginal Medical Service <input type="checkbox"/> Service Provider Network <input type="checkbox"/> Network/Support Group <input type="checkbox"/> Other (.....) <input type="checkbox"/> (.....) <input type="checkbox"/> (.....)
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6. Do your clients have to pay for the palliative care service?
 If so can they reclaim it from Medicare or a private insurer? (which?)

7. What aspects of your palliative care service do you consider works very well and why? Tell me the one thing that is best or most significant about your service?
 - 7a Any other things that work well

8. If there was one thing about your service that could be improved on – what would it be and why?
 - 8a Any other things that could be improved on?
9. How (and by whom) are clients referred to your service
10. What sort of assessment tools do you use to determine that they are palliative care clients and what their needs are?
 - 10a Does the assessment include the family or only the client?
 - 10b Do you sometimes refer people on? To Whom? How does that happen?
11. Describe your relationship with other Service Providers?

(Prompts: Which ones, what sort of services do they provide and are they mainstream or indigenous specific services?)

 - 11a Can you give me an example of where things work well (with other service providers) and why – and an example of things that could be improved?
12. Are there barriers to Aboriginal or Torres Strait Islander people accessing palliative care services? What do you think they are? What do you think could be done about them?
13. What sort of information is available to Indigenous people about palliative care and what gaps are there?
14. Do you have any comments about the level of, or need for training? *(Prompt: palliative care training or cross cultural training)*
15. What sort of palliative care specialist support or expert consultation is available to you and your staff?
 - a) How important is this?
 - b) How often and in what circumstances do you use this support?
16. You might have covered this already – Do you offer bereavement services – describe? – or How is bereavement dealt with by Indigenous clients?
17. What sort of contact does your organisation have with the Aboriginal community and in particular with:
 - a) ACCHS, (if not an ACCHS)
 - b) ALO at hospital,
 - c) Community organisations (which ones)
 - d) Other
18. There has been a lot of talk about standards in Palliative Care lately? What do you think makes a good palliative care service? What would you say are the 3–5 most critical things?
19. Are you familiar with the Palliative Care Australia (PCA) Standards? YES or NO? If yes: Do you consider the PCA standards are relevant for services being delivered to Indigenous clients – is there any thing you would add, subtract or change? If you are not familiar with them – don't answer the question
20. Do you have any comments on the level or nature of palliative care training of staff in your service or the nature and availability of palliative care training?
21. That is nearly the end of the questions except for some statistical stuff. Is there any thing you would like to add about what you consider are the unmet needs in Indigenous palliative care or about how families cope when someone is sick and not going to get better or after someone passes away after such an illness? Do they have enough help? What sort of assistance would they need that they might not be getting?

22. What are your hours/days of opening?

23. Client Numbers

a. Number of palliative care clients?

Total (Financial Year) 2000/2001 patients:

% Aboriginal and Torres Strait Islander:

% Aboriginal:

% Torres Strait Islander:

% Indigenous PC clients by age	% Non-Indigenous PC clients by age
0 – 10:	0 – 10:
11 – 20	11 – 20
21 – 30	21 – 30
31 – 40	31 – 40
41 – 50	41 – 50
51 – 60	51 – 60
61 – 70	61 – 70
71 – 80	71 – 80
80+	80+

b. Total current Indigenous patients:.....

24. Staff

Number of staff	Male staff		Female staff	
	Indigenous	Non - Ind	Indigenous	Non - Ind
Management:				
Admin:				
Doctor:				
Nursing:				
Health Worker:				
Advocate:				
Community Liaison:				
Driver:				
Volunteers				
Other				

25. Levels of training:
- a. Number of Staff with Cross Cultural Training:
 - b. Number of Staff with Palliative Care Training:
What sort of palliative care training?
 - c. Number of Staff with Indigenous Palliative Care Training:

26. Source of palliative care funding:

	Percentage	Type of funding (AHCA, HACC, Flexible, Multipurpose etc)
Australian Government Health:		
State Government:		
Local Government:		
AMS:		
ATSIC:		
Community:		
Church:		
Charity/Not For Profit:		
User Pays:		
Other:		

Level of Palliative Care Funding (Annual Budget)\$:

If these questions do not fit your situation please describe your funding arrangements on a separate sheet.)

27. Information about respondent

- a. In relation to working in palliative care would you describe yourself as:
 - Very experienced Somewhat experienced Relatively new/inexperienced
- b. What about working with Aboriginal and Torres Strait Islander palliative care clients?
 - Very experienced Somewhat experienced Relatively new/inexperienced
- c. Do you identify as an:
 - Aboriginal person
 - Torres Strait Islander
 - Aboriginal & Torres Strait Islander person
 - Non-Indigenous Person

ATTACHMENT E

IPCSS Model Recruitment Guide

Dear Recruiter,

You will already have received advice from us about the number of interviews or discussion groups we would like to you to arrange, when they will be held, and so on.

We have prepared a guide for you to use in recruiting people for the interviews and group discussion about Palliative Care being undertaken by us for the Australian Government Department of Health. Kate Sullivan and Associates Pty Ltd is an independent research firm, which guarantees confidentiality. The interview team will include Aboriginal or Torres Strait Islander members.

The study aims to find out what services are available to Aboriginal and Torres Strait Islander people when a family member is diagnosed with a life threatening illness which cannot be cured. The research will ask people what sort of issues arise for them when someone is sick and won't get better and won't get better and might be close to passing away.

We are interested in talking to a cross section of the community, however it will be most useful to us if the people we interview have something (either good or bad) to say about this subject. The discussion subject is a sensitive one and peoples' experience of Palliative Care or the need for it, is the most important criteria (or reason) for asking them to take part in the discussion.

As you will be aware we need **about 5 people in each group**. We suggest that you recruit 7-8, then if one or two don't turn up that will not matter. Overall we would prefer **equal numbers of men and women** and would like a spread of ages between 18 and 60.

There is no problem if the people coming know or are related to each other. It would probably be better for our research though, if the people coming live in **different households** [that is, we would not want four family members who all live in the same household].

The guide attached suggests the way in which you should invite people to attend. We suggest you stick to the order given in the guide, but please feel free to put it into your own words so you feel comfortable about it.

It is important that anyone who is recently bereaved (ie within the last six months) is not recruited.

We have provided a sheet for you to record the names of those attending. It may be a good idea to ring people the day before and remind them that they are coming.

We look forward to hearing from you soon and to meeting you when we visit.

Sincerely,
Kate Sullivan

Discussion group about Palliative Care

Meeting Date:

Meeting Place:

Name	Sex/age	Agreed	Phone number	Day before Confirmed
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Attendance

I have signed the 'informed consent' form and I declare that I answered all questions truthfully and accurately when being recruited. I acknowledge that any monies or gratuities received by me regarding this project are accepted for expenses incurred and I agree that I am the person whose signature appears below.

Name

Amount received

Date

Signature

RECRUITMENT GUIDE: INTERVIEW ABOUT PALLIATIVE CARE

Introduce yourself – etc.

I have been asked to get find a small number of Aboriginal people (or Torres Strait Islander people) who are aged (18-30 or over 30) years to talk about their experience of what sort of services are available to help people who have or had a family member who is or was diagnosed with a life threatening illness for which there is no cure. The research is being funded by the Australian Government Department of Health and Ageing and being conducted by independent consultants including Aboriginal researchers.

I have been asked to say that the discussion subject is a sensitive one and that if you have recently had a bereavement you should not attend.

Have you suffered a close bereavement in the last six months? If the answer is 'yes' thank them for their time and explain that we are not including anyone in this category. If the answer is 'no' proceed.

Are you between the ages of 18 and 30? or (Are you older than 30)?

The study aims to find out what services are available to Aboriginal and Torres Strait Islander people after a family member is diagnosed with a life threatening illness for which there is no cure. **The research will ask people what sort of issues arise for them when someone is sick and won't get better and may be close to passing away.** The study is being undertaken so that the Aboriginal and Torres Strait Islander needs can be taken into account in Australian Government policy and planning in relation to Palliative Care.

The interview will be confidential and no information will be provided to anyone which could identify you.

Would you be available to be interviewed about this subject?

When would you be available on Date:.....

Time:It will take 1 1/2 hours

Would you like the interviewer to come to your house or would you be prefer to come to

Place:

(If the person would like to talk to the research team and would feel more comfortable about attending the discussion group see if you can fit them into a discussion group.)

Will you be able to take part?

- My number, in case you need to get back to me, is:
- Can I have a contact phone number for you just in case I need to get back to you.

Thank you very much.

ATTACHMENT F

Indigenous Palliative Care Needs Scoping Study Media Strategy

Aims

- Create general awareness of the research project
- Prompt individuals to make contact and share their experience with consultants
- Raise awareness of Indigenous Palliative Care issues
- Generate interest and awareness in regions where field work is being conducted (see below)

Stages

It is suggested that media activity to support the fieldwork be conducted in two stages. The first stage would be aimed at generating general awareness of and interest in the project through

- targeted stories prepared for Koori Mail and National Indigenous Times (fortnightly national Indigenous papers, alternative weeks)
- a general media release or media briefing provided to ATSIC Radio and main (ie largely regional) Indigenous media organisations; and interviews if media outlets pick up the story

This activity would primarily be aimed to encourage people working in the palliative care field, or Indigenous people who have had personal experiences of palliative care (or the lack of it), to make contact and contribute their experiences to the research.

Note: apart from ATSIC Radio and the two national newspapers, there is not a mechanism to achieve national coverage of the story for Indigenous audiences. Regional Indigenous media organisations (mainly radio and print) will need to be targeted and selected with care as the issue is likely to be considered very sensitive in some regions.

A second stage could be targeted to publicise the research activity in specific regions where field work. This will be conducted at stage 7 of the project, however whether to proceed would need to be considered and decided as part of the field-visit methodology and would require the agreement of Indigenous partnership organisations. If it is agreed that media activity would be helpful, the second stage media activity would be discussed and agreed with the partnership organisations in each region. Generally it would involve:

- media releases/briefing materials provided to local media organisations in the specific regions
- follow up approaches to media outlets and liaison to arrange interviews

A final stage 'wrap up' round of media activity could be conducted towards the end of the project (approximately Stages 8-9) to inform Indigenous audiences, in particular, and mainstream audiences of the outcomes of the research.

ATTACHMENT G

Newsletter photo consent form

I agree to have my photo taken today (insert date)..... at (insert location).....

I understand that the photo may be published in the newsletter about the Palliative Care Study and or in a news story about the study and I agree / do not agree (*strike out which ever does not apply*) to have my name published in the caption to the photograph. I understand that the photo will not be used for any other purpose without my special written permission.

Signed

Appendix 7



Stage 6 Needs survey, headline summary

Needs Survey – Headline Summary

1. Responses from Aboriginal Aged Care providers
2. Indigenous Government Health Services – Indigenous CACP providers etc
3. Western Australian Service Providers
4. Service Providers from States Other than WA
5. Responses from Community Controlled Health Organisations

Needs survey – headline summary

230 questionnaires were sent out to:

- 132 Community controlled Health organisations,
- 55 Flexi-funded or residential Aboriginal Aged Care hostels or nursing homes
- 43 Newsletter respondents (people who had responded to the previous newsletters wishing to contribute)

The main issues raised in the survey responses are reported below. The responses are reported in the following groupings:

1. Responses from Aboriginal Aged Care providers
2. Indigenous Government Health Services – Indigenous CACP providers, etc
3. Western Australian Service providers
4. Service providers in states other than Western Australia
5. Responses from community controlled health organisations

1. Responses from Aboriginal aged care providers

Note: these facilities all have a majority of non-Indigenous workers.

How palliative care works in our area

Rural: Aboriginal Aged Care facility (low-care) in WA

Family choose to look after relative: home and community care provide daily checks. MS provide medication. If the family can't manage, the person is hospitalised until sent away (at least 250k) for high care placement or they pass away in hospital as placement can take a long time.

Need for local low and high care places. Nearest palliative care bed is 45km away and there is one bed only.

Main issue is that people want to die at home, amongst their own people.

Family should be given a choice to look after person at home with nursing care available.

Remote: Aboriginal Aged Care facility in WA

Works with local palliative care team who do assessments and consult. If scheduled drugs are needed on the weekend (when the RN is off duty) a palliative care RN will come in.

Needs:

- Better Facilities For High Care Patients
- Education on PC matters for staff.

Things that make a good service:

1. Pain relief,
2. Counselling (if residents want it) and good communication,
3. Compassionate carers, family and friends support,
4. Good nursing care.

Remote: Aboriginal Aged Care hostel in SA

Health Service have health workers that monitor clients and when illness becomes serious the clients are admitted to hospital for pain relief and high quality care. Local hospital is very aware of cultural issues and makes the clients comfortable as requested by individual families. An aged care facility (Australian Government funded) is being built adjoining the hospital, comprised of 6 high care, 6 low care beds and 6 independent living. This will be a huge advantage as people want to die in their own area. Ngangkari are sought in these times.

Main issues:

- To die in their own area of birth is a big issue as family members insist that they come back to this town – as it is the ‘right way’ spiritually
- Comfort, quick and easy services
- Confidentiality on issues
- *Ngangkari*

In our new aged care facility currently being built we have set aside an area for ‘sorry camp’ which is a private area for grieving, shielded from onlookers.

At our bush camp we have two separate areas a short distance away for grieving activities to occur.

Aged care

Aboriginal nursing home and hostel in rural South Australia:

Many clients are referred from the north and west of the state. Need for palliative care is discussed with resident and family members. Nursing home provides the care with the support of the AMS and the palliative care team from the hospital.

Needs:

- Improved facilities to house palliative residents to allow greater comfort to residents and families.
- Improved (more frequent) access to traditional healers – spiritual – traditional care. (visits of Ngangkari are facilitated when they are in town – but it is not regular)
- Easier access to / more frequent visits from AMS medical officers would assist care provision.

Things that make a good service:

1. Adherence to residents’ and family personal choice of care provision including culturally appropriate care and traditional care where possible
2. Adequate pain management – maintain comfort
3. Liaison with palliative care nurses, medical officers and allied health professionals

4. Access to spiritual (traditional where required) guidance
5. Training for staff specific to palliative care.

From the Aged Care respondents generally

Information sources – Knowledge

All respondents emphasised word of mouth as being the most likely source of knowledge including from:

- Families – community grapevine
- Health services, health workers and doctors

One facility emphasised that they were reliant on interpreters to explain the philosophy of palliative care.

Traditional issues

- Smoking ceremonies and vacating rooms undertaken
- Assistance with funerals is provided
- Bereavement is generally left to family and homeland communities

Training

- In one aged care facility all staff have 2 days cultural awareness training and policies reflect multiculturalism.
- Staff and RNs would benefit from palliative care training. Care would improve with training.
- Need for in-service training for health workers – suggested it be delivered by the local PC RN

Other issues – needs

Need for financial assistance for families (from outlying communities) to stay in town with their relatives

Responses reflected the fact that unless patient's own country was very close to the facility, then patients were not able to die at home. (*Note: the impossibility of this seems unchallenged.*)

'Mostly indigenous people want to die 'at home' (in their community) which is impossible to facilitate – mostly they die in hospital if we (aged care hostel) can't care for them.'

2. Indigenous Government health services – Indigenous CACP providers etc

Rural NSW (Mental Health Worker)

Family help followed up by health workers (Indigenous and non-Indigenous).

The services which exist are two CNC's (education and consulting role) for an area the size of Tasmania but with a large Indigenous population. Indigenous palliative care workers would assist with cultural barriers. These mainstream services currently liaise with Aboriginal Health workers to get background information.

'Palliative care services ease the burden of stress for the client and family and friends.'

The main issues for Aboriginal people are support and follow up. Currently people find out about the services by referral, but if the service found out from Aboriginal health workers which community members were terminally ill this would reduce the gaps. (*Note: Implications: the need for ongoing communication between palliative care service providers and Health Workers*)

‘There are Aboriginal mental health workers in this area. It is important to ask the family first and not to assume that the service (mental health) is wanted. Aboriginal Health Workers can follow up when they hear of an illness. Traditional healers would be good but there are none in this area.’

Rural NSW – Aboriginal Housing Corporation – CACP provider

‘No Indigenous palliative care services exist in XX or YY (adjoining) Shires. There is very little in the way of mainstream palliative care services. (I don’t know of any specific service that I could contact). As a general practice, I allow my CACP program to extend into palliative care to fill the gap. I have also used the services of the Area Health Carer Respite Centre for extended care. They have provided resources.’ (primarily funding for carer hours)

‘In my experience most families choose to have patient at home, although many of my clients have died in hospital. The needs are:

- 1. hospital beds that move (sit up)*
- 2. extended care hours for care workers and*
- 3. adequate budget for other equipment.’*

How do community members find out about services?

‘They usually come to our service or the AMS to seek appropriate services. Generally speaking the community is aware of most client situations.’ (ie community members who work in these services know what is going on with other community members).

Clients do not pay for services.

Are the services provided the right sort of services?

‘Kooris have control (some) of services provided within their own homes. They are often critical of hospital services (when client spends last days there). Unsure of level of support provided by Koori Hospital Liaison Worker.’

Do people use mainstream services?

‘They don’t use current available services. A specific Koori liaison worker would promote confidence among the Koori community.’

Main issues..?

‘In-home care a prerogative. Carers either Koori or if not, the carer needs sensitivity to cultural issues.

There is very little information available.’

Counselling services?

‘Have had difficulty accessing counselling services. Anglicare operates a phone service. Local Community Health Centre has counsellors but difficult to get appointment.

‘Counselling services are also an issue for care workers involved and for myself as coordinator. Deaths here are fairly constant and this is an ongoing problem. I had to broker in-training for grief and loss from the grief centre in Melbourne at great cost to the service. Nothing else available re training.’

Who helps people with sadness and sorry feelings...?

‘Our services would have the most expertise but we are seldom contacted in this regard.’

Cultural practices...?

‘Assistance (usually financial) is often provided to the family of deceased re funeral, or wake. Also travel assistance often provided to people who have to travel to funeral.’

Other issue(s)?

‘There is no Koori-specific nursing home, aged care facility in these two adjoining Shires. The closest is in Victoria in the south or xxxx to the north. Local Kooris will not leave their county to access these facilities – this puts pressure on local services to provide this. Also no Koori Respite House in the area – another problem. Where do people go for a break?’

Rural Victoria

One response from an ALO at a small district hospital. She was not aware that there had been any Indigenous palliative care clients, but spoke highly of the palliative care service at the hospital. She saw it as her role to promote these services in the community and to ensure that services would be appropriate.

She did not think that there would be any problems with Indigenous people using the ‘excellent’ services that existed. She thought that the major issues would be for people to be respected and treated with dignity in a culturally appropriate way. She said that she had posters, pamphlets and brochures but it is not clear if these are Aboriginal specific.

There are social workers at the hospital and at Community Health and a counselling brokerage fund for private psychologists etc – but it is not clear if these services are or have been used by Aboriginal people.

She described the community as a contemporary community having funeral service at churches and smoking ceremonies at the cemetery if people wanted it.

3. Western Australian service providers

Barriers to Indigenous people accessing services

Remote area Homecare service

- lack of knowledge/promotion of services
- needs to be promoted within Aboriginal community
- language and literacy

‘The main barrier is cultural difference. Once they use the service they appreciate it. It is difficult to get education to Aboriginal services. We take referrals from AMS and liaise frequently. The main problem is staff turnover at the AMS and therefore their knowledge of the service and palliative care generally.’ (Rural MS PC Co-ord)

Remote nursing home

Lack of transport. Limited access to care in remote areas. Limited knowledge of availability – inability to have last days at home due to remoteness

Limited knowledge of dying process (need education, brochures)

It would be good to be able to have the support of the family so that people could go home to die when that is what they want.

Training issues

'Have tried to take education to Aboriginal people in 2001 with no success. Need to revisit method that was used and try again. Continual battle to access funding to provide education and training in our area. Able to use technology is a great help.' (Rural MS Palliative Care Co-ord)

Funding for cross cultural training would be most welcome – recently poor response to advertised program because of cost. (Rural hospital Palliative Care Co-ord)

Training difficult to access because of distance. (Palliative Care – remote)

Bereavement

Funerals are a large part of the bereavement process (Remote nursing home)

What makes a 'good palliative care service'

'A service that provides the best possible care for clients and families in a facility of their choice
– *Care for patient*
– *Standards of symptom control*
– *Standards of terminal care*
– *Bereavement services'*

Rural MS Palliative Care Co-ord

- respecting clients wishes (including culture)
- client is informed of choices
- comfort / dignity of client

Rural/Urban Palliative Care Community Nurse

- Good symptom Management
- Holistic care
- Enough money – well used.

Remote nursing home

- staff education
- family support
- team consultation and planning

Rural/urban hospital PC Co-ord

- Aiming to be culturally appropriate at all times
- Open lines of communication between all professionals and having approachable team members for the patients and families
- Active quality program

Needs and issues

Being aware of Indigenous culture is vital. Families that have used our service appreciate that we can help and are a resource that assists both clients and families.

Getting palliative care known to the Indigenous community is a problem. (MS Palliative Care Co-ord)

Greater numbers of appropriately trained Indigenous staff members (Palliative Care remote)

A better plan of care is needed with the treating GPs eg RFDS doctors treating one resident repeatedly – need a cohesive care plan.

Things that work well

Good allied health support as a result of being connected to the hospital.

All the WA service provider respondents said how useful the 24 hour, 7 day a week phone line was.

4. Service providers from states other than WA

Barriers to Indigenous people accessing services

NSW ALO

- Lack of information /knowledge of service
- Cultural barrier/ misunderstanding
- Service not effective in accessing Koori community.
- Need more education, and to increase profile of service with the community.

NSW Doctor

The services are mainstream. Requests for things like a family room at the hospital have been denied in the past.

NT nursing home manager

- Language
- The nursing home is run by non-indigenous people with limited cross cultural training.

North Queensland

Distance is a barrier – outlying stations and settlements

Information availability

No Indigenous specific information to disseminate

Training Issues

1. Lack of training – across the board
2. ALO, AHEO, AMS staff need training and info on current services (ALO NSW Area Health)
3. *Our own staff (especially health workers) need increased awareness training (about palliative care). Mainstream palliative care staff need cross cultural training and a higher profile in or community.* (AMS)
4. *Cross cultural training for mainstream staff and palliative care training for carers.* (NT Nursing home)
5. *Difficulty to replace staff who are going on training* (Aboriginal community hospital Qld)

Bereavement

MS NSW Bereavement service provided includes assistance with arranging funeral, liaison with Land Council and Centrelink counselling and referrals if required.

'... (rural city in NSW) has a large Indigenous community; as a result many people deal with grief and bereavement in a 'normal' way within 'normal' timeframes. However, due to what may be a series of losses, some people are at an increased risk of dramatic changes in behaviour and socially unacceptable behaviour as a way of dealing with bereavement'
(ALO Area Health Service)

What makes a 'Good palliative care service'

ALO rural NSW

- Being culturally appropriate
- Knowledge of disease, course of disease etc
- Pain control and relief

AMS Doctor NSW

- Caring people who are experienced and well trained
- A good multi-disciplinary team that understand their relationship
- Coordinated delivery of services.

NT Nursing home manager

- Pain management
- Support for client and family
- Meeting wishes of dying client

PC coordinator Qld country Hospital

- Knowledge of services that exist
- Maintenance of funding
- Confidentiality

Needs and issues

Adequately trained staff to provide culturally appropriate services

‘We as an organisation need to ask the people what they want and need. I’ll put this to our Health Action Group.’ (Indigenous nursing service in an Aboriginal community in Qld)

Things to improve

NT Nursing home manager

- Funding to access equipment
- Funding for training and education
- Cost effective cross cultural training especially relating to pain, death, dying and grieving process
- Funding to send clients home
- Accessible and cost effective interpreter service.

Queensland Community

- Size of room in hospital and air conditioning.

North Queensland

- Two centres report that they do not believe that there are barriers to access.
- One of these had an Aboriginal palliative care worker.
- The other is centred on an oncology department so if the client had cancer they will be referred to the palliative care team. This service may not be seeing non-cancer related cases.

5. Responses from community controlled health organisations

Small community not far from Brisbane

‘Good access to mainstream services (home nursing). This is good because they allow people to be cared for in their own environment. Aboriginal people prefer to be cared for in their own environment so therefore these services are appropriate, providing choice for client in who cares for them and where.’

Needs:

1. Support in areas of grief and loss
2. Understanding of processes in regard to death and dying
3. Culturally sensitive services

Nth Qld. small town with large Aboriginal Population

'People cope – best they can, varies between families. There is a palliative ward at the local hospital but it is not culturally appropriate; often the attitude of the nurses is poor. There are no at home services (apart from the Blue Nurses – who are overworked) and there is no counselling help for the family and patient.'

Information about services comes from the AMS or word of mouth.

'The hospital often tries to accommodate our needs, but are often not culturally appropriate.'

'You have to be in the local hospital in order to access the palliative care services, although once you have been admitted or can attend as often as necessary. The staff in the palliative care ward are good but the rest of the hospital often does things the 'wrong way' (either through ignorance or not enough time or staff). There are stigmas associated with the hospital and often people don't like the air-conditioning.'

What would need to change:

1. Indigenous staff,
2. Services separate from the hospital,
3. Easier access and
4. Culturally appropriate information

Counselling is offered only to in-patients. The AMS family support worker might help.

Northern Territory (Community Controlled Health Organisation)

People find out about services through their GP or Community Clinic. The main issue for Aboriginal and Torres Strait Islander peoples is to have a choice of where the patient wishes to receive care, ie. in hospital or at home in their communities; and making sure that families are available to help care for the patient if the patient wishes to stay at home.

People use the mainstream services. There are no counselling services. Family helps with sorry feelings.

Western NSW – a Community Controlled Health Organisation)

The response reported that the only help for people with life limiting illness is the ALO and Uniting Care meals. Meals have to be paid for. *(Note: It is likely that the response reflects the knowledge of the person filling it in rather than reality, however it is significant that it came from a Community Controlled Health Organisation and indicates the poor level of knowledge about palliative care services.)*

Appendix 8



Indigenous view of hospice needs

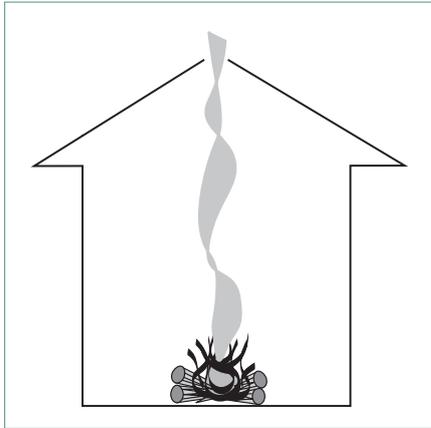
An extract from a letter sent by Top End Palliative Care Service (AHW) to communities expressing Indigenous View on Hospice

The Northern Territory Government on behalf of Health and Community Services has proposed to build a hospice on the grounds of the Darwin Hospital. The hospice will include a 12-bed in-patient ward and the Community Palliative Care team.

In order to make the proposed Hospice culturally appropriate and user friendly for Indigenous people the Aboriginal Health Worker has been seeking support and comment from Aboriginal organisations, health professionals and community members throughout the Territory. The Department of Health and Community Services (DHCS) will be asked to take into account the following points to meet Indigenous needs:

1. Rooms to open onto verandahs, large windows which can be seen out of, high ceiling (feeling of space);
2. Individual temperature control and ability to turn off air-conditioning;
3. Rooms to allow for smoking ceremony;
4. Adequate sound proofing of rooms to allow for expression of emotional grief (crying, wailing), songs, dance and ceremony;
5. Privacy to feel comfortable when conducting or carrying out traditional cultural activities/practises;
6. Rooms to accommodate bed for relatives who wish to stay bed side;
7. Special area with bed etc. for visiting Aboriginal people who are in [major regional centre] for the day visiting a specialist clinic in Out Patient's Department. Some people are very weak and sick and need somewhere they can rest comfortably whilst waiting long hours for tests or to catch a plane back home to their community;
8. Area in grounds for bough shelter and beach sand for people who wish to use this area for resting or ceremony;
9. Grassed area to accommodate large groups of Aboriginal people who may be at a family meeting, involved in ceremony or waiting for someone to pass away or attending a viewing of a deceased relative;
10. Area for children to play outside;
11. Activities room for children inside hospice. Culturally Aboriginal children are involved/exposed to death and dying process and will be spending long periods at hospice with family;
12. BBQ or cooking area for traditional food;

13. Constructed hollow for a fire to sit around with family or to organise/prepare special ceremonies eg. smoking.



Suggestion of fire place example from CARPU Alice Springs copied from North American Indians

14. Rooms near private area situated in corner of hospice to prepare for /perform ceremonies.
15. Welcoming and support for traditional healers role.
16. Employment of an Aboriginal Health Worker and Aboriginal Liaison Officer to work with urban community and hospital clients.
17. Native plants in garden.
18. View of ocean for saltwater people and Territorians. We do not want another square box like building eg. the existing hospital. Building to reflect lifestyle of all Territorians .
19. Accommodation for immediate family.

Several other issues were raised by respondents to the letter including:

- need to be able to put beds outside in a private courtyard area;
- need to look at issues (Occupational Health & Safety) around looking after a client on a mattress rather than a bed; and
- transport issues for clients.

Appendix 9



Hospital meeting room for an Aboriginal community

DRAFT PROCEDURE: Use of the Minyah Barmah Room

DATE: 02.08.01

EXPECTED OUTCOME:

Family members of Aboriginal and Torres Strait Islander patients currently admitted at Goulburn Valley Health will have access to Minyah Barmah room and its facilities and use of the Minyah Barmah room is in accordance with Goulburn Valley Health guidelines.

Action	By whom	Relevant standards
Appropriate use of the Minyah Barmah room		
<p>'Minyah Barmah' means spiritual meeting place. The Minyah Barmah room is a place where Aboriginal and Torres Strait Islander people can come for a yarn, a cuppa, or just to sit, while a family member is in hospital. Family members may seek to use the Minyah Barmah room in many circumstances, including, but not limited to, the dying patient; patients in critical conditions; or childbirth for example. The Minyah Barmah environment can play an important role at such times in assisting family members to cope, and in turn to support the patient.</p>	All	EqUIP: Standard 1: Access Criteria 1.1.1,1.2.5
Normal opening hours		
<p>The Minyah Barmah room will be open from 8a.m. to 8.p.m. each day, including weekends and public holidays.</p> <ul style="list-style-type: none"> The Minyah Barmah room will be un-locked at 8a.m. each morning. The Minyah Barmah will be locked at 8p.m. each night. <p>During normal working hours, use of the Minyah Barmah room will be co-ordinated through the Aboriginal Liaison Officer.</p>	Security staff A.L.O.	EqUIP: Standard 1: Access Criteria 1.1.4
Approval of extended hours access		
<p>Normal opening hours will apply except in the following circumstances:</p> <ul style="list-style-type: none"> Prior arrangements have been made with immediate family members and the A.L.O., and this has been communicated to the after-hours co-ordinator At the discretion of the After Hours Coordinator in accordance with the needs and circumstances of the family. 	A.L.O. After-hours co-ordinator	EqUIP: Standard 1: Access Criteria 1.1.4
Extended hours access arranged by the A.L.O.		
<p>The Aboriginal Liaison Officer will notify the After-Hours Co-ordinator if it is known that immediate family members of a critically ill patient:-</p> <ul style="list-style-type: none"> are to continue their stay in the Minyah Barmah beyond 8p.m. at night; or are likely to seek access to Minyah Barmah after-hours 	A.L.O.	EqUIP: Standard 1: Access

Action	By whom	Relevant standards
<p>In these circumstances the A.L.O. will advise the After Hours Co-ordinator about how many family members will be using the room, and when they will be leaving or arriving. Ideally, the ALO will also provide the names of those using the room during extended hours. The ALO is responsible for:</p> <ul style="list-style-type: none"> explaining to family members that this information is required for GVHealth to meet its safety obligations, and; advising families that it is preferred that the numbers attending be kept to no more than 4 immediate family members. 		
Security provisions during normal opening hours		
<p>The following procedures are to be followed:</p> <ul style="list-style-type: none"> The Minyah Barmah room is to be unlocked at 8am each morning and locked at 8pm each evening unless otherwise advised by the After Hours Coordinator. 	Security	EqUIP: Criteria 5.1.1, 5.1.4, 5.1.5
<ul style="list-style-type: none"> The duress alarm to be activated earlier rather than later in situations of violence or unrest. 	ALO	
<ul style="list-style-type: none"> An incident report is to be completed and forwarded to the Director, Community & Integrated Care within 24hrs each time the duress alarm is activated. 	ALO	
Security provisions for extended hours use		
<p>The following procedures are to be followed:</p> <ul style="list-style-type: none"> The After Hours Coordinator is to advise security that a family has use of the Minyah Barmah room, including how many people, and how long they are likely to remain. 	After-hours co-ordinator	EqUIP: Criteria 5.1.7
<ul style="list-style-type: none"> If security discovers any persons using the Minyah Barmah room that they have not be advised of by the After Hours coordinator, security are to contact the After Hours coordinator, who will determine whether the extended hours use is appropriate. 	After-hours co-ordinator	
<ul style="list-style-type: none"> If, on the advice of the After-hours co-ordinator no authorisation is granted to individuals to continue extended hours use of the Minyah Barmah room, the security attendant has the right to ask the individuals to leave. 	Security	
<ul style="list-style-type: none"> An incident report is to be completed and supplied to Director Community & Integrated Care in regard to any incidents occurring after-hours in the Minyah Barmah room. 	After-hours co-ordinator	
Supplies		
<p>Tea, coffee and milk are available free of charge. To ensure that costs are contained:</p> <ul style="list-style-type: none"> these supplies are for use only within the Minyah Barmah room, 		EqUIP: Standard 1: Access Criteria 1.2.1
<ul style="list-style-type: none"> additional supplies will only be issued by Hotel Services on direct request from the ALO. Hotel Services are not authorized to release supplies to anyone other than the ALO. 	ALO Hotel services	
Telephone		
<p>A telephone is provided in the Minyah Barmah room which will allow incoming calls to family members, and internal calls within GVHealth.</p>		
Meal Vouchers		
<p>The Aboriginal Liaison Officer Program has a limited budget available to provide meal vouchers to support family members of Aboriginal patients in critical situations. To ensure that this service is kept within budget and is available to those most in need, the issuing of meal vouchers through the ALO program is restricted to the following circumstances:</p>		EqUIP: Standard 1: Access Criteria 1.2.5
<ul style="list-style-type: none"> Meal Vouchers can be issued to immediate family members of a patient in the Intensive Care Unit and in Palliative Care only. No more than 4 immediate family members are to receive meal vouchers. Immediate family members include the spouse or partner of the patient, parents of the patient and the children of the patient. 	ALO	
<ul style="list-style-type: none"> One meal voucher is for one standard meal for one person. Refreshments are not included with the meal voucher. 	Hotel services	
<ul style="list-style-type: none"> Meal Vouchers are only to be made available in these circumstances on request to the Aboriginal Liaison Officer. 	ALO	
<ul style="list-style-type: none"> Access to meal vouchers will cease once a patient is transferred from the Intensive Care Unit to another ward. 		

Appendix 10

Indigenous-specific funding for aged care and nursing homes

Aboriginal and Torres Strait Islander residential aged care services funded under the *Aged Care Act 1997* in January 2002.

STATE	NAME OF SERVICE	SUBURB/TOWN	P/CODE
NSW	Booroongen Djugen Aboriginal Corporation	Kempsey	2440
NSW	Rose Mumbler Village	North Nowra	2541
NT	Juninga Centre	Nightcliff	0810
NT	Hetti Perkins Hostel and Nursing Home	Alice Springs	0870
NT	Pulka Pulka Kari	Tennant Creek	0860
NT	Rocky Ridge Hostel and Nursing Home	Katherine	0850
Qld	Dija Meta Aged & Disabled Hostel	Cairns	4870
Qld	Fred Leftwich Rest Home	Mareeba	4880
Qld	Nareeba Moopi Moopi Pa Aged Care Hostel	Dunwich	4183
Qld	Yarrabah Aged Persons Hostel	Yarrabah	4871
Qld	Hopevale Aged Hostel	Hopevale	4871
Qld	Jimbelunga Hostel and Nursing Centre	Eagleby	4207
Qld	Ny-Ku-Byun Hostel	Cherbourg	4605
Qld	Ngooderi House Hostel	Doomdgee	4830
Qld	Kukajar Place	Normanton	4890
Qld	Mornington Island Aged Persons Hostel	Mornington Island	4871
Qld	Torres Strait Home For The Aged and Star Of The Sea	Thursday Island	4875
VIC	Maloga Home	Nathalia	3638
WA	Ngurra Karnpi	Kalgoorlie	6430
WA	Yaandina Frail Aged Hostel	Roebourne	6718
WA	Yulanya Nursing Home	Port Hedland	6721
WA	Mirtanya Maya Frail Aged Hostel	Port Hedland	6721
WA	Marlgu Village	Wyndham	6740
WA	Halls Creek Peoples Church Hostel	Halls Creek	6770
WA	Germanus Kent	Broome	6725
WA	Numbla Nunga Nursing Home	Derby	6728
WA	Guwardi Ngadu	Fitzroy Crossing	6765

STATE	NAME OF SERVICE	SUBURB/TOWN	P/CODE
WA	Ngamang Bawoona Hostel	Derby	6728
WA	Olive Laird Memorial Home (Ingada Village)	Carnarvon	6701
Aboriginal and Torres Strait Islander Flexible Aged Care Services, January 2002			
NSW	Brewarrina Aged Accommodation Association Inc	Brewarrina	2839
NSW	Canowindra Tweed-Byron Aged and Disabled Aboriginal Corporation	South Tweed Heads	2485
NSW	Goodooga Flexible Care Service/Far West Area Health Service	Bourke	2840
NSW	Jack Towney Hostel	Gilgandra	2827
NSW	Narrandera Wiradjuri Elders Group	Narrandera	2700
NT	Mabunji Aboriginal Resource Association Inc	Borroloola	0854
NT	Mamapa Maninja-Kurlangu Jarlu Patu-Ku Aboriginal Corporation	Yuendumu via Alice Springs	0872
NT	Angurugu Community Government Council	Alyangula	0885
NT	Anmatjere Community Government Council	Ti Tree via Alice Springs	0872
NT	Maningrida Danila Dilba Biluru Butji Binnilutlum Health Service Aboriginal Corporation	Darwin	0801
NT	Nguiu Tiwi Health Board	Darwin	0801
NT	Kaltukatjara (Docker River) Kaltukatjara Community Council	Docker River via Alice Springs	0872
NT	Katherine West Health Board Aboriginal Corporation	Katherine	0851
QLD	Injilinji Aboriginal and Torres Strait Islander Corporation for Children and Youth Services	Mt Isa	4825
QLD	Georgina Margaret Davidson-Thompson Hostel	Morningside	4170
QLD	Palm Island Old Peoples Home	Palm Island Townsville	4810
QLD	Shalom Elders Village	Thuringowra Central	4817
SA	Aboriginal Elders Village (AEV) Aboriginal Elders & Community Care Services Inc (AECCS) / Italian Benevolent Society	Davoren Park	5113
SA	Konibba Aboriginal Health Services Inc	Ceduna	5690
SA	Umooona Community Council Inc Aged Care Services	Cooper Pedy	5723
SA	Wami Kata Old Folks Home	Port Augusta	5700
TAS	Flinders Island Aboriginal Association Inc	Whitemark	7255
TAS	Tasmanian Aboriginal Centre (TAC)	Hobart	7001
VIC	Aboriginal Community Elders Service (ACES) Iris Lovett Gardiner Centre	East Brunswick	3057

Appendix 11



Example of a nursing home standard Re: cultural practice

‘YYY’ Frail Aged Hostel Policies and Procedures: Death and dying

Policy

To ensure that care practices respect spiritual cultural and religious values of residents and their families,

Aboriginal culture

In the Aboriginal culture it is inappropriate to discuss dying with the resident or their family and therefore is difficult to obtain information prior to a death. It is appropriate for the Hostel Manager or staff to talk in the Aboriginal dialect of [], (the word for death) to other residents or family members.

Procedure

- Resident’s wishes concerning their terminal care are identified on admission. It is not appropriate to discuss dying with Indigenous people for cultural and spiritual reasons. This is to be respected. Terminal care is documented on the admission assessment database. Consideration must be given to legal and ethical issues pertaining to the resident’s wishes.
- The hostel is unable to provide palliative care and specialised clinical care, therefore if a resident becomes ill and requires these services they will be transferred to a hospital or high care facility.
- In the event of a resident requiring transfer, see discharge /transfer policy.

What to Do

Remember any medical emergency dial 000 or local Ambulance or Hospital,

on

finding a deceased resident, call:

D. Doctor at AMS

After hours call

Hospital

Pastor DS

Police

Family Members

A medical officer is to confirm the death and write a certificate. Relevant details of the death and procedure following death must be recorded in the Residents progress notes,

‘YYY’ Frail Aged Hostel Policies and Procedures: Death and dying Aboriginal culture procedure

- If a death is expected, the resident may be transferred to the hospital due to care requirements but also due to the cultural issues affecting Aboriginal staff carrying out their duties and the problem with room occupancy after the death.
- The room must remain empty until the funeral has taken place, which can take up to several weeks depending on the community and family location,
- The residents should not get into the deceased's room until after the ‘Smoking’ ceremony. An appropriate Aboriginal person within the community must perform the ceremony. The hostel staff shall assist in the organisation and co-ordination of the ceremony.
- Notify the Fire Brigade of the date and time of the ceremony, as the alarms will be deactivated during the ceremony.

The other residents at the Hostel are, notified of the death during the day and are given support and time in which to grieve. Grieving may involve wailing, handshaking and touching shoulders and staff are encouraged to sit with the residents during this process.

Assistance will be given to residents wishing to attend the funeral if they wish to do so.

Please Note:

- Personal belongings of deceased resident will be collected and given to the next of kin listed on the Admission Summary.
- Following departure of deceased resident, discard soiled linen and clean the room according to usual protocol.

This Policy and Procedure relates to:
Standard 2,5 12.9 / 3.8 / 3.9 / 4,7

Appendix 12



Regional network guidelines – A draft example

Regional network guidelines on palliative and bereavement care for Aboriginal people

1.1 Introduction

A number of palliative care service providers from the [rural area] region in Victoria (see attached list) met at [4AA] Aboriginal Co-operative Ltd on 7 August 2002. The idea for this meeting of service providers in the regional network came from [], the Manager of Aged and Disability Services at [4AA], who had identified the need for such a meeting to develop some protocols or guidelines for the way palliative care is provided to Aboriginal people and families in the region. The meeting was facilitated by team members from the National Indigenous Palliative Care Needs Scoping Study Project¹. The team members had spent several days interviewing individual service providers and some Aboriginal community members prior to the meeting.

Three objectives were established for the first network meeting day, and for the network as a whole:

1. To learn what each group does and what our expectations are of each other. The mainstream service providers especially wanted to know what the [4AA] Aboriginal Co-operative offered;
2. To develop ways to work with each other better and in a culturally appropriate way; and
3. To develop a document which sets out what has been agreed about how to work together and what action needs to be taken.

1.2 Resolutions

1. The meeting decided that:

Aboriginal palliative care service provider network meeting will be held regularly. Initially it will be held monthly on the first Wednesday of each month, with the venue to rotate between network members. Meetings will be held from 10am till 12 noon. The first meeting to be held at [4AA] on 4 September 2002.

*2. The meeting decided to document the following issues and solutions as **Network Guidelines** and agreed that:*

The Network Guidelines will be formally reviewed and renewed in August 2003.

¹ The project is funded by the Australian Government Department of Health and Ageing.

1.3 Network Guidelines (draft)

1.0 Service providers working together with [4AA] Aboriginal Cooperative.

Service providers and [4AA] Aboriginal Co-operative should develop individual sustained and active agreements about how to operate, based upon dialogue, shared expectations and information, and based on face-to-face contact, shared work experience and mutual respect.

2.0 Identification of Indigenous Status

Always ask about Indigenous status of client *and* their family and explain why the question is being asked. Note that sometimes family members may be of Aboriginal and Torres Strait Islander descent even if the primary client isn't.

3.0 Understanding Cultural Context

- 3.1 Aboriginal people are generally not used to having non-Aboriginal visitors. For many the only non-Aboriginal or non-family members visiting their homes in the past will have been people like 'the welfare' or 'the police' and many Aboriginal people still have strong fears of outside visitors because of the long history of stolen children.
- 3.2 Many Aboriginal people will not tell you if they do not understand what you are saying and will not ask questions out of politeness.
- 3.3 Many Aboriginal people have a very different spiritual reality from most westerners. Do not assume that what the family or client is telling you is due to medication or pathology. Many Aboriginal see previously deceased family around them when they or family members are close to death.
- 3.4 Do not make assumptions about the roles and relationships of family members (eg carer, decision maker, advocate). There may be complex cultural issues involved in who takes what role when.

4.0 Cultural Awareness – action needed

- 4.1 Seek development and inclusion of a palliative care component or palliative care focus into existing cultural awareness training packages available;
- 4.2 All service providers should undertake cultural awareness training;
- 4.3 Do not assume that you will understand 'Aboriginal culture' because you have had cultural awareness training. There are many variations across Australia. Be aware that there is a different cultural reality to your own.

5.0 Relationship development and continuity of staff

Issue:

Where care is delivered at home there seems to be a constant stream of non-Aboriginal strangers in the home – especially in the early stages. (These may be several people from the one service and/or people from a number of services.) In some cases this resulted in Aboriginal people rejecting services.

Solutions and suggestions:

- 5.1 Where possible and appropriate make sure there is an Aboriginal community representative, liaison person or advocate present at the initial meetings and until the client and family is comfortable before their presence is withdrawn. The Aboriginal community representative should be acceptable to the client and family and may in fact be a family member.
- 5.2 Allow sufficient and appropriate time for the early meetings and be prepared to go back and revisit several times. Several shorter visits might be better than one long one.
- 5.3 Be prepared to re-schedule meetings or visits if other family or community business intervenes. Be culturally sensitive in this matter and remain flexible.
- 5.4 Build consistency:
 - Endeavour to have consistency in team members visiting – limit the number of new faces, especially early in the relationship;
 - Make introductions of team members – consider using and leaving a photo of the whole team;
 - Try to forewarn clients if a new or different person will be coming and explain why.
- 5.5 Take the time to build trust by
 - Explaining to the family who is in the team, who provides what services and what the family should expect (and not expect) from these services and about the progress of the disease;
 - Asking what the client and families expectations and hopes are of the service.
- 5.6 Use plain language, be yourself and ask for feedback to check that information has been understood:
 - Use active listening skills;
 - On the next visit check information that was given previously;
 - Leave written versions behind wherever possible and appropriate;
 - Acknowledge that there is a lot to be taken in and that it is likely to sound complicated.
 - Be culturally aware – many Aboriginal people will politely say that they understand rather than ask for clarification.
- 5.7 Provide copies of care plans or a letter setting out expectations and agreements.
 - Leave or send at least two copies so that families can use one copy to show around.

6.0 Referrals and Assessment

6.1 When making or receiving referrals:

- Re-ask the Indigenous status question in relation to the client and their family;
- Inform the client of the options of having an Aboriginal community liaison representative and/or appropriate family members involved from the outset;
- Check with the client whether Aboriginal liaison services have already been involved, and if so who and in what context.

6.2 When making or receiving assessments:

- Make sure an appropriate Aboriginal liaison person is present;
- Be aware that the main carer, family contact person, Aboriginal community representative and decision makers may be different people;
- As the relationship develops be aware of the different roles of family members. Roles may be different in different circumstances;
- In preparing bereavement risk assessments, be aware of the likelihood of multiple losses;
- Be prepared to go back and revisit to get all the information you need for an assessment (see also relationship development).

7.0 Shared care

When there is shared care there should be on-going case management contact involving the Aboriginal community liaison person or relevant family member.

8.0 Quality assessment and feedback

At intervals, invite an Aboriginal third party (probably an ALO) who is independent of your service to visit the client and family and ask how it is going. What is going well, and what could be improved? The ALO can then report to the service provider and any necessary action be taken.

9.0 Bereavement planning

Generic bereavement care plans should be reviewed in liaison with experienced Aboriginal community palliative care workers and the staff from the Emotional and Social Wellbeing unit of the Community Controlled medical services to ensure that they are culturally appropriate.

10.0 Debriefing needs of Indigenous palliative care workers

All workers should be sensitive to the debriefing needs of Aboriginal palliative care workers who, while fulfilling their professional role in a case, may also be among the bereaved due to close community relationships.

11.0 Information

11.1 Gather, share and lobby for Indigenous-specific information about palliative care and palliative care resource materials.

11.2 Try to take steps to see that information is available where Aboriginal people can access it.

11.3 Encourage people making referrals (especially hospitals and GPs) to provide appropriate information about palliative care to Indigenous clients.

12.0 Access to services

Palliative care workers should be aware that:

- the distance between (and difficulty of access to) Indigenous-specific services; and
- the client's likely distance from any palliative care services puts pressure on already limited resources and makes equity of access difficult.

13.0 Volunteer recruitment and training

A deliberate effort should be made to raise awareness of volunteer training in the Koori community. Recruitment and training should be reviewed to ensure that it is culturally appropriate.

14.0 Funding for Aboriginal liaison/community based palliative care coordinator

There is a recognised need for funding for an Aboriginal community based palliative care coordinator role, including appropriate training, professional supervision and debriefing). One potential source of funds for this role is the use of unassigned palliative care funds (usually set aside for ancillary services) to purchase Aboriginal community-based palliative care coordination or Aboriginal liaison from services where these roles already exist.

15.0 Potential action for the hospital

- 15.1 The Minya Burmah is a recognised valuable cultural resource. Disseminate information (internally and externally) and educate (internally) about the use and protocols of the Minya Barmah room.
- 15.2 Increase the number of ALOs at the hospital, especially the number involved in the hospital care process for palliative care clients.
- 15.3 Arrange cultural awareness training for the social work department.
- 15.4 Hospital, in partnership with [4AA], to investigate what needs to be done so that appropriate information is given to Aboriginal or Torres Strait Islander clients about options for place of death and place of burial.
- 15.5 Ensure appropriate Aboriginal representative presence at discharge meetings for palliative care clients.
- 15.6 Develop a palliative care pathway with Aboriginal liaison and cultural information and referral options built into it. This will involve a review (in partnership with [4AA] and palliative care service providers) of current information and information delivery by the hospital, medical staff and the local Division of General Practice.

1.4 Attendance List

Name	Role	Phone number	Email contact
	Aged and Disability Care Manager, [4AA] Cooperative		
	Coordinator, Emotional and Social Wellbeing [4AA] Cooperative [4AB] Hospice Care Service [4AB] Hospice Care Service		
	Director, Community and Integrated Care, [4AC] Base Hospital		
	Aboriginal Liaison Officer (Acting) [4AC] Base Hospital [4AD] Palliative Care [4AD] Palliative Care		
	Bereavement Support Worker [4AE] Regional Palliative Care Coordinator, District Nursing, [4AF] Health		
	Community Interlink		
	Executive Director, Kate Sullivan and Associates Pty Ltd		
	Consultant to Kate Sullivan and Associates Pty Ltd		

Appendix 13



Funding background

1.0 Aboriginal and Torres Strait Islander funding

The following sources of funds have been identified by informants as being used for Palliative Care for Indigenous clients. Not all of these are legitimately accessed for palliative care.

1.1 OATSIH funding

OATSHI funds 120 Community Controlled Medical Services (AMSs) throughout Australia. These services receive grant funding on a global budget basis.

These services can also access funds via Medicare and pharmaceutical funds either through the Pharmaceutical Benefit Scheme or under Section 100 of the National Health Act (if they are remote). These organisations may also receive some State grants and access other Australian Government funds through special programs.

We do not know the full extent of the palliative care provided by community-controlled medical services. We do know that it is being provided usually informally and that no specific funding is provided for it. As these organisations are 9.00 –5.00, 5 day-a-week services, any palliative care services they deliver must be limited.

The Primary Health Care Access Program announced in the 1999-2000 budget, which is still in the process of being rolled out, has three objectives:

- Increase the availability of appropriate primary health care services where they are currently inadequate;
- Reform the local health system to better meet the needs of Indigenous people; and
- Empowering individuals and communities to take greater responsibility for their own health.

'PHCAP will establish a framework for the expansion of comprehensive primary health care services, including clinical care, illness prevention and early intervention activities and management and support systems, in a planned and coordinated manner in line with regional planning.' (see www.health.gov.au/OATSIH/pubs/phcap/)

The scheme is dependent upon regional planning processes having been completed and essentially allows top-up funding to fill gaps in service delivery. Advice from the Health Financing Section is that nearly all the regional plans are now complete and that *Palliative Care has not been identified as a priority in any of them.*

1.2 Aged Care funding – flexible care

Multipurpose Funding

For communities of less than 5,000 people Multipurpose Service (MPS) funding is available. This funding comes from the Aged Care bucket but is administered by the regional health Services Section of the Department.

This funding arrangement allows the pooling of a range of funds and allows a community to focus upon its priorities while making major savings on administration.

The Multipurpose Services Program is a joint Australian Government, State and Territory Government initiative that aims to provide a more flexible, coordinated and cost-effective framework for health and aged care services in rural areas.

Australian Government funding for aged care is pooled with State funds for health services, usually acute care. The program provides a range of services that necessarily include residential aged care, and may also include acute hospital, palliative care and community nursing, home care and meals on wheels, integrated services for young children, mental health, podiatry and women's health. (www.dotrs.gov.au/regional/statement/consolidation/older_improving.htm)

There are 63 MPS in Australia. For 62 of these the State government is the service provider. For one of these an Aboriginal community-controlled health service is the provider. This community controlled health organisation was one of the organisations identified to us in the initial scoping as providing 'good practice' palliative care for Indigenous clients.

Indigenous Flexible Funding

The Aboriginal and Torres Strait Islander Flexible Aged Care Services Program provides small services with the flexibility to respond to changing community needs. It provides the capacity for a mix of high, low and community care services. Currently, 24 of these services (providing 356 flexible care places) are funded, with an additional 29 mainstream Indigenous services in rural and remote areas (see below).

It is our understanding that Indigenous Flexible Funding (and Residential Care Funding – see below) are generally not available for palliative care. 'Unless palliative care is specifically in their funding contract they shouldn't be providing it.' However where their Indigenous clients become ill or reach the end of life palliative care is often provided. This may apply to hostels rather than to nursing.

At least one service provider funded under this scheme, with whom we spoke will not approach State or Australian Government for palliative care funds for cultural reasons. They do not like the label 'palliative care'. Culturally they feel unable to make a decision that someone is dying and therefore will not ask for special funds for this, despite the fact that the level of service (especially medical or nursing) which they provide at the end of life is well beyond their budget.

Indigenous nursing homes (as opposed to aged care facilities) are in no doubt about their deliberate provision of palliative care services.

Several services under this funding model were identified to us as providing some palliative care services (eg Wami Kata in Port Augusta, ACES in Victoria).

Residential Care funding

There are two types of residential aged care: high care and low care, formerly known as nursing homes and hostels. Most are operated by religious, charitable, local government or private providers. Some are operated by State governments.

There are 31 Indigenous programs funded under the Mainstream Residential Care arrangements.

EACH – Extended Care at Home

Hospital in the home – no information as yet.

Community Aged Care Packages (CACPs)

Community aged care is equivalent to low level residential care service, but is delivered in the person's own home. It may include personal care, home help, delivered meals and other community-based care services. There are special packages set aside for Indigenous people.

1.3 Home and Community Care Funding HACC

There used to be a small amount of funding for palliative care under the HACC program but recently palliative care has been declared a 'no growth' component of HACC. This means that only programs in which it used to be an approved part of the program can continue to use funds for it, and these will not be increased. Current descriptions of HACC programs do not include palliative care as a component.

This is of particular concern for Indigenous palliative care. HACC services have been very successful in establishing Indigenous HACC programs. It is Indigenous HACC workers who often identify palliative care needs and informants tell us that HACC workers often provide informal and unfunded services to palliative care clients. This is partly because for Indigenous people it is more important to have a 'black face' providing a service than to have specialist strangers in the home.

Below are some extracts from the HACC Programme descriptions provided by the HACC Outcomes Branch of the Australian Government Department of Health and Aged Care.

Who does the HACC programme assist?

The Programme assists people in the target group who need basic maintenance and support services to continue living in the community with dignity.

Clause 4 of the HACC Amending Agreement provides that the Programme shall be directed towards assisting:

- a) the target population comprising persons living in the community who, in the absence of basic maintenance and support services provided or to be provided within the scope of the Program, are at risk of premature or inappropriate long term residential care, including:
 - i) older and frail persons, with moderate, severe or profound disabilities;
 - ii) younger persons with moderate, severe or profound disabilities; and
 - iii) such other classes of persons as are agreed upon by the Australian Government Minister and the State Minister; and
- b) the carers of persons specified in sub-clause (a).

While the term ‘older and frail persons’ is used in the definition of the target population for HACC services, it should be noted that eligibility for services is based on frailty related to handicap and that individuals do not qualify for HACC services solely on the grounds of advanced age. Thus, individuals over any particular age do not qualify for HACC services on the basis of their age alone, but because they have difficulties in carrying out tasks and need assistance due to a moderate, severe or profound disability.

Special needs groups

Within the overall HACC target population there are several groups that find it more difficult than most to access services. These are people with cultural or other special needs.

The groups are:

- people from culturally and linguistically diverse backgrounds;
- Aborigines and Torres Strait Islanders;
- people with dementia;
- financially disadvantaged people; and
- people living in remote or isolated areas.

HACC funded services can be provided specifically for one or more of the above groups either by a generic service or, where appropriate by a specific service.

What is the scope of the programme?

The Programme is intended to provide basic maintenance and support services that are cost effective and meet the needs of individuals so they can remain in the community.

Basic maintenance and support services are defined as those essential to a person’s well being, for example nutrition, community nursing, home help and personal care. Others, such as information and training courses, enable a greater level of understanding and expertise to be built up among service providers and consumers about the care of frail aged people and people with disabilities and the needs of their carers.

Excluded services

The HACC Amending Agreements enable the expansion of services which provide basic maintenance and support to the Programme’s consumer group. They specifically exclude from funding certain other services.

The excluded services, also known as ‘out of scope’, are classed as such because funding is already provided for them through other government programmes. Excluded services are:

- accommodation (including rehousing, supported accommodation, and aged care homes or a related service);
- aids or appliances (wheelchairs, crutches, etc). This is because separate programmes in each State and Territory provide these items. However, where items are required for the operation of an eligible HACC service and would remain the property of the service (that is, not become the personal property of an individual user), they are eligible for funding; and

- direct treatment for acute illness (including convalescent or post acute care) except for basic maintenance and support to people within the target population following an acute care episode. That is, HACC is responsible for providing basic maintenance and support services to eligible clients who need post-acute care, while health services are responsible for providing the 'specialist' component of post-acute care.

'No growth' services

Some services previously funded under the four Acts* incorporated into the *Home and Community Care Act 1985* have been designated as 'no growth' services under the HACC Programme, so that organisations offering these services may not expand them using resources from the HACC Programme. Any expansion of these services must be funded from other sources.

These limitations were imposed because the legislation preceding the HACC Act 1985 had more broadly defined purposes and target groups than HACC. The HACC Programme was unable to take responsibility for providing growth funds for some aspects of pre-HACC services. To do so would have led to the diffusion of HACC objectives and the spread of limited resources over too many services. Growth in these services must be funded through more appropriate sources including other Australian Government, State and Territory programmes.

No growth services include:

- rehabilitative services – involving therapy which assesses and improves general physical and mental functioning;
- specific disability services – such as a service specifically for people with a physical disability. This does not include services for people with dementia or a related disorder;
- services primarily for families in crisis – such as assistance to ease or provide additional support during a crisis in the family, for example multiple births; and
- palliative care services; that is, care for a person in terminal stages of illness.

It should be noted however that basic support and maintenance services are still available for people in the HACC target group who may also be receiving the above types of services.

* The four Acts are: *Home Nursing Subsidy Act 1956*, *States Grants (Paramedical Services) Act 1969*, *States Grants (Home Care) Act*, and *Delivered Meals Subsidy Act 1970*.

Appendix 14



Job descriptions

Sample job descriptions

1. Indigenous palliative care development and promotion officer

This role is designed to work at a local level with mainstream palliative care services to assist them to develop their services so as to provide culturally sensitive services, and to assist them to work with Aboriginal and Torres Strait Islander health and home care services for integrated service delivery. If similar positions were envisaged at a State or regional level, some of the duties would need to be expanded to include work with other professional bodies, industry associations and policy makers. A state level role might require a higher skill level.

The Indigenous Palliative Care Worker will:

1. Work with Service Providers to develop their services so they are appropriate to Aboriginal and/or Torres Strait Islander clients and community.
2. Facilitate communication between palliative care service providers (including ancillary and tertiary services) and Aboriginal and/or Torres Strait Islander services by organising regular network meetings focused on Aboriginal and/or Torres Strait Islander issues.
3. Provide or arrange education/information to Indigenous Health Workers, hospital ALOs, HACC services, medical staff in Aboriginal Medical Service (and other professional bodies as necessary) to explain what palliative care is.
4. Arrange the delivery of tailored cultural awareness training by qualified trainers.
5. Coach service providers (including palliative care specialists, domiciliary nurses and allied health professionals) in developing cultural awareness and in attaining competencies in effective cross cultural practice. Assist with relationship development between mainstream services and the Aboriginal and/or Torres Strait Islander communities.
6. Review literature and information material such as brochures on palliative care or related issues and work with service providers to develop culturally appropriate materials.
7. Undertake appropriate promotion activities with Aboriginal and/or Torres Strait Islander community groups or leaders.
8. Be willing to undertake formal palliative care training (eg 4-5 day training suitable for Enrolled Nurse or volunteer or similar) if not currently qualified.

The successful applicant should have minimum qualifications of Enrolled Nurse or Aboriginal Health Worker (preferably with a post graduate certificate in palliative care) and must be Indigenous. Indigenous tertiary qualified staff (nurses, psychologists and social workers) may be required in some locations.

Depending upon the size of the region involved and the size of the Indigenous population, this position could be part time and/or services could be arranged by brokerage.

Even though it may be funded through a mainstream service provider, the position could be located within an Indigenous organisation – for example, the Aboriginal Medical Service – where the person would have support from other Indigenous staff and could possibly undertake other health worker duties within the service.

2. Indigenous palliative care worker

The role of this position would be to provide hands on, day to day cultural and or medical advocacy for Indigenous palliative care clients. Such a position would work closely with palliative care specialist doctors and nurses and be a part of the palliative care team. The preferred qualifications for this position would be tertiary qualifications in nursing, social work or psychology, but in many places it may be more realistic to set minimum qualifications of AHW or EN with post graduate qualifications in palliative care (should such courses become available).

Duties

The duties of this position should be tailored to the particular requirements of the location and organisation, but would include:

- hands on, day to day contact with palliative care clients
- preparedness to be involved in regular professional debriefing
- undertaking cultural awareness orientation for the area in which they would be working if they were not from that area

Duties may also include some of those outlined above for an Indigenous palliative care development and promotion officer.

Depending upon the size of the region involved and the size of its Indigenous population, this position could be part time with services arranged by brokerage.

If the position were to be located within an Indigenous organisation – say the Aboriginal Medical Service – the person would have support from other Indigenous staff and could possibly undertake other health worker duties within the service.



For more information about the
National Palliative Care Program,
please contact our freecall enquiry
line on **1800 020 787** or visit
www.palliativecare.gov.au

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