

*Providing culturally appropriate palliative care to
Aboriginal and Torres Strait Islander peoples*

Discussion Paper




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Prepared for the Australian Government Department of Health and Ageing
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ISBN 0 642 82371 5

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Publication Approval Number 3371



Acknowledgements

The production of this Discussion Paper was funded as part of the National Palliative Care Strategy by the Australian Government Department of Health and Ageing's National Palliative Care Program. It was produced by Professor Ian Anderson and Dr. Jeannie Devitt.

The cover illustration and artwork design of this document was painted by Aboriginal artist Jane Walsh of Victoria.

Note to the revised edition

Differently from other sections of this revised edition of the *Resource Kit*, no alteration has been made to the text of this discussion paper to replace the term 'Indigenous Australians' with the preferred term 'Aboriginal and Torres Strait Islander peoples'. This course of action has been taken because the paper was produced as an academic work independently of the rest of the Kit and it was therefore inappropriate for the project team to make changes to the text.






Foreword

The aim of this Discussion Paper is to inform and add value to the Practice Principles and education and training Resource in Aboriginal and Torres Strait Islander Palliative Care.

It seeks to provide an understanding of the experiences and general beliefs about death and loss that are unique to the indigenous world view in general and Australian Aboriginal populations in particular.

This is examined in the light of intercultural communication challenges experience by health service providers faced with the unique experiences and beliefs of Aboriginal and Torres Strait Islander peoples. The focus is on the broad principles and processes that underpin the uniqueness of the Aboriginal and Torres Strait Islander peoples perspective, rather than specific myths and rituals which cannot be generalised across Aboriginal and Torres Strait Islander cultures.

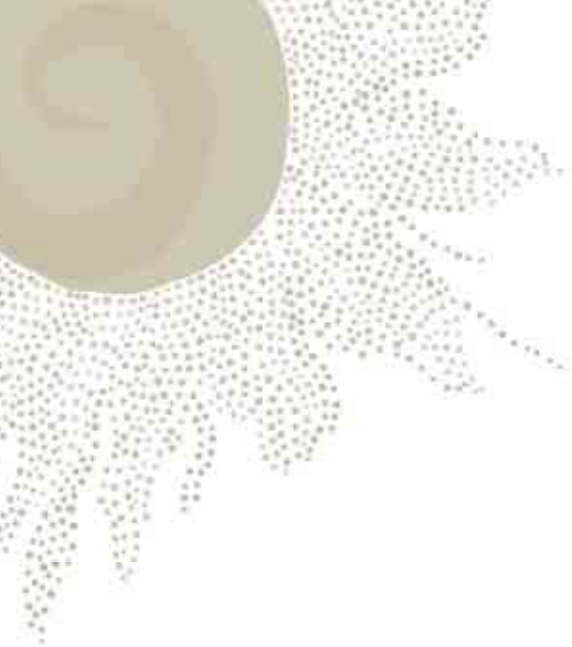
The final section of the Discussion Paper includes a summary of the basic principles of intercultural communication and issues around implementing these in Australia, and a significant section on practice recommendations.



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Introduction

Context

This Discussion Paper was developed in response to the need to better understand the unique experiences and beliefs around death and dying held by Indigenous Australians. Whilst Australia has long been recognised as a multi-cultural society, Indigenous Australian culture is unique to this country rather than being imported from another country. The Discussion Paper sought to identify if or how these experiences and beliefs have impacted on palliative care provision to Indigenous Australians.

The Discussion Paper provides an overview of existing literature relating to Indigenous Australian perspectives and issues around death and dying. It identifies key themes recurring in the literature. It has provided a complementary perspective to the feedback generated from consultation with palliative care service providers, Aboriginal Health Workers and Liaison Officers and within Indigenous Australian Communities.

The Discussion Paper has informed the development of the two accompanying documents forming this education kit – the Practice Principles and the Resource – particularly in relation to cultural safety, values and ethics, reflective practice, the centrality of place (land), the importance of kin and family and the on-going issues around death and dying in Indigenous Australian communities.

The Discussion Paper aims to provide an understanding of:

- the experiences and general beliefs about death and loss of Indigenous Australians. Where relevant we have drawn on the experience of other Indigenous populations
- the intercultural communication challenges that palliative care service providers face with these unique experiences and beliefs, in particular outlining an approach to engaging with social and cultural diversity in health care settings.



Using a thematic approach, critical concepts or considerations relating to death/dying and intercultural communication have been drawn from the literature. These are:

- shifting paradigms
- 'culture'
- cultural racism
- cultural safety
- values and ethics
- reflective practice.

Key themes in the literature are identified. These include:

- historical responses of Indigenous Australian communities (accommodation, incorporation and rejection)
- centrality of place
- kin and family
- continuity of life
- the relationship of spirit, soul, place and time
- frequency of experience of death
- sensitivity of the topic of death
- diversity of post-death rituals.

Implications for palliative care provision are presented within a framework of working with difference. The Discussion Paper looks at system level responses, cultural safety, and addressing 'culture'.

The thematic approach of the Discussion Paper is supported by a summary of statistics relating to patterns of death of Indigenous Australians in contemporary Australia.

Brief

Our brief for the Discussion Paper for the Indigenous Palliative Care Practice Principles Project included two main tasks.

- 1 To review the literature on Indigenous experiences of death and loss with a view to providing:

'an understanding of the experiences and general beliefs about death and loss that are unique to the indigenous world view in general and the Australian Aboriginal populations in particular.'

- 2 Provide an understanding of the intercultural communication challenges to health service providers faced with the above unique experiences and beliefs.

A third task of the brief — identifying 'frameworks and tools' to facilitate intercultural communications — has been undertaken by other project team members, resulting in the two companion documents forming this education kit, the Practice Principles and the Resource. The work completed under Objectives 1 and 2 will contribute to the development of the training resources. We deal with the objectives in Section 2.2 *Death and dying* and Section 3 *Intercultural Communication*.

Ultimately, given the scope of the subject, we have referred in a limited way to other Indigenous groups.

The review methodology is provided separately in Appendix 1 as required by the project brief. We also present a brief statistical description of mortality in contemporary Indigenous Australian communities (Appendix 2). This data gives a quantitative dimension to our more qualitatively directed review; giving comparative shape to the context within which Indigenous Australians are currently experiencing death. So, for example, the subjective experience of 'epidemic' death in some age groups is strongly supported by the statistics of loss.

Use of terms

Consistent with other Department of Health and Ageing materials, the term 'Indigenous Australian' has been used where possible. It encompasses Aboriginal and/or Torres Strait Islander peoples.



Preface

In a recent volume, *Death and Dying in Australia* Kellehear (2000:9) suggested that:

'... Australian ways of grieving, Australian ideas of death and some Australian ways of thinking about disposal are not logical or natural outcomes of our local experience but are rather socially constructed ways of understanding inherited from a variety of dominant foreign influences.'

He describes the formative historical and social influences on ways of death, dying and loss (p1) as including, firstly, race relations history, then a series of effects flowing on from broader, global, social change, namely: secularisation, medicalisation, Americanisation, and gentrification. Within this paradigm, Indigenous Australian people's own constructions of death are — from the outset — located somewhat on the edge of the historical trajectory of the proposed changing nature of 'Australian ideas of death.' In a globalised, 'post-modern' context where *the idea of an 'Australian' way of anything becomes a place of contested meanings*, Indigenous Australians are seen as one group among the modern 'many' within a rapidly changing Australia.

Arguably, however, Indigenous Australian people's ways of dying and their ideas about death can also be understood as *the* quintessentially 'local' experience. Like other people, Indigenous Australians' understandings of death and dying are 'socially constructed'. Nevertheless, they can be seen to embody the 'local experience' in ways that are both particular to themselves and distinctively Australian (Berndt 1998:39, Morphy 1984b). The emblematic expression of that 'local influence' is in the centrality of highly elaborated and socially encompassing notions of 'place' understood both geographically and ecologically. While this distinctive conceptualisation embodies the responses of literally hundreds of generations of individuals to their particular localities, as Kellehear notes, such responses are neither 'natural' or 'logical' but remain 'cultural' and 'social'. The sheer diversity of social practices concerning death and dying that are observed by Indigenous Australians — both historically and now — is convincing evidence in support of this.

As a tiny minority in contemporary Australia, Indigenous Australians' ways of death *are* simply one strand of a broader fabric of diverse and changing practices, subject similarly to myriad influences, foreign and other. But that one strand emerges from within Australia, from within this locality, in a way unlike any other. In that sense, within Kellehear's proposition, the Aboriginal and Torres Strait Islander experience can be clearly distinguished from that of other Australians.

As elsewhere, death is a relatively recent topic of focused social scholarship in Australia. The terms 'death' and 'dying' encapsulate a complex subject with individual, social, emotional, cultural and other dimensions. Death, as an event, is investigated from a multitude of disciplinary as well as theoretical positions. Commonly recognised dimensions and/or stages in the event include bereavement, grief and loss, mourning, and the preparation and disposal of the body and associated rituals. Hockey (Hockey 2001:4-5) provide the following helpful definitions:

- *The term bereavement refers to the state of being bereaved or deprived of something ... bereavement identifies the objective situation of individuals who have experienced a loss.*
- 'Grief' is primarily an activity and refers to the emotional, as well as other response/s, to death and loss.
- 'Mourning' usually indicates the process of coping with loss and grief and the ways in which individuals and societies incorporate this process into their new reality.
- 'Death ritual' ... describes what people do when they have experienced the loss of an individual. Death rituals can be public or private, or both. Such rituals may have a prescribed 'format'. Nevertheless, each enactment incorporates refinements that reflect the current reality.

We also suggest adding a further category, 'preparation for death', for situations where a person's death is known to be imminent. This period, which may be lengthy, incorporates the dying person's own preparations for death as well the nature of the changing relations between themselves and those around them, including kin, friends, carers and other service providers. Since this period also involves health/care, rituals of preparation, as well as determinations of death, it is pervasively enmeshed with state instrumentalities (health services, family supports, aged care, palliative care, accommodation, assets disposal, etc).



This framework usefully distinguishes the individual/personal experience of death from the more public, social response/s evident in, for example, death rituals. The literature on the subject of death also clusters long similar lines. For example, the relevant anthropological literature is heavily dominated by considerations of the public, social response to death through its analyses of death rituals, mourning customs and the like. There is little commentary or reportage on individual, personal experiences of grief and bereavement (Reid 1979:326).

However, as Hockey et al (2001:5) suggest, this kind of division around public/private, inner/outer experience if rigidly applied also masks the complex relationship that exists between the *apparently 'internal' individualised emotions* (like 'grief') and the social and cultural contexts within which particular deaths are experienced. The many dimensions – affective, cognitive, behavioural, etc – of the experience and expression of grief will reflect the particular social setting of the individual. Thus, *both* the personal, seemingly 'private', experience as well as the public expressions of grief, bereavement and disposal are interconnected such that *there is a complex and reflexive relationship between emotionality, subjectivity and social practice* (Hockey 2001:20). How we experience as well as express emotions is shaped by our personal life histories as well as social (including historical) and cultural influences. This is the case for individual experience as well as public collective forms of expressions. It may be also that the emphasis on the individual so characteristic of western society obscures the social – as well as the cultural – dimensions of grief and bereavement, and contributes to a common (western) perception that grief is largely a private and personal matter (Griffin and Tobin 1997:31).

1 Critical concepts and considerations

Using a thematic approach (see methodology in Appendix 1) we have drawn a number of critical concepts or considerations from the literature, both those related to ‘death/dying’ and those related to ‘intercultural communication’. These are important in several ways: some assist in critically reviewing the literature (for example, shifting paradigms), some relate to resource preparation (for example, inter-disciplinary borrowing) and some might properly be subjects of study by practitioners and so be the subject of specific resources (for example, culture, racism, cultural safety, values and ethics). Some concepts have bearing on all of these aspects of the project.

1.1 Theory and paradigm shifts

The anthropological literature relevant to the subject of death in Indigenous Australian societies spans more than a hundred years. More recently, there is also a burgeoning literature from other disciplinary perspectives: health, sociology, psychology and so on. All the literature is underpinned not only by a number of explicitly drawn theoretical approaches but also by differences in implicit assumptions about the nature of the ‘other’. Disciplinary paradigms shift continually; our understanding of the subject itself evolves (Kellehear 2002:176).

Key in the case of the anthropological literature are understandings of the relation between the past, present and the future, specifically concerning the concept of ‘tradition/traditional’ (Harris 1996). Post-modern insights into the social construction of knowledge and the partial nature of ‘truth’, as well as the critical views of Indigenous Australians themselves, have implication for reading back into earlier anthropological literature. The literatures of diverse periods, locations and authors are not comparable. In particular, they may add little to the kind of understandings necessary for a truly responsive contemporary service. Services are interactional. For example, the practitioners are actively engaged with clients, jointly negotiating their (sometimes) very different perspectives on situations. They are ‘in’ the encounter in a way that observers and researchers are not. In some cases, reportage itself is both inaccurate and offensive.



Making a similar point in relation to the particularly pertinent subject of religious and spiritual practices, Swain (1985:134) cites Berndt's observation that *'the understanding of Aboriginal religion has been greatly affected by theories ABOUT religion'* (original emphasis). The study of Australian religions and spirituality was initially undertaken by anthropologists committed to an evolutionary paradigm in which religion and spiritual practices were understood as a lesser form of consciousness than science. Aboriginal belief systems were generally considered as 'elementary'. Only in more recent decades has the serious scholarly consideration of Aboriginal spirituality as a religious system emerged (Charlesworth 1998:xv).

Disciplinary paradigms and the theoretical pre-occupations which shape what is observed, as well as how it is documented and interpreted, are themselves constantly evolving and shifting. Similarly, the status of the 'evidence' and its meaning will remain open to re-interpretation.

1.2 'Culture'

There is no agreed definition of the term 'culture' (Seymour-Smith 1986:65) even within the discipline of anthropology which, until comparatively recently, claimed a virtual monopoly on the scholarly development of the concept. At its broadest, the term 'culture' refers to those aspects of human life that are socially learned, transmitted and reproduced. Culture is an attribute of groups as well as of individuals. The culturally-based assumptions and premises that individuals hold are (mostly) implicit and unarticulated in their everyday life. The concept of 'culture' also includes notions of those shared sets of values and frameworks for social action which shape — without determining — the behaviour of individuals and groups within any given society. Since culture is continually transformed through the social actions of both individuals and groups, it is characterised as much by change and transformation as by continuity.

In a study of a contemporary Indigenous Australian (Yolngu) social theory of health and illness, Jan Reid describes the potential for change, ambiguity and personal innovation within a specific 'cultural' framework, noting that:

'Belief, like action, is socially situated, socially reproduced and socially revised. The continuing value of beliefs for believers lies in their capacity to give meaning to social and natural phenomena. When social, political and economic relations change and when customary modes of social action no longer produce the desired ends, believers, like scientists, must either live with the anomalies or abandon or revise their models of reality. Thus, change in belief cannot be understood independently of the social transformations which precipitate doubt and dissonance.' (Reid 1983: xxiv)

Morris and Cowlshaw usefully distinguish between, the anthropological/ sociological understandings of 'culture' as *a whole way of life, with more or less unconscious and habituated patterns of behaviour* and, a commonly-assumed popular or 'folk' understanding of culture as largely an 'outer' phenomenon, where it *refers to a chosen way of life or 'lifestyle', as expressed in aesthetic forms and voluntary social practices* (1997:5). Morris and Cowlshaw see the essential contrast in these different understandings of culture as being that of an 'inner' phenomenon as opposed to an 'outer' one, where the terms respectively refer to a '*given essence*' or a '*chosen surface*'. A full consideration of 'culture' recognises both dimensions and, moreover, the complex relationship between them (see earlier comments by Hockey). The pervasiveness of the term 'culture' in everyday life (for example, pop culture, organisational culture, et cetera) only increases the likelihood of a health and health services discourse where key terms are differently understood and/or applied.

Within Australia, anthropologists have played a dominant role in the public representation of Indigenous Australian cultures. In a critical review, Cowlshaw (1992) argues that Australian academic knowledge acquired through 'studying Aborigines' has been firstly, for purposes unrelated to the social groups in question, and secondly, has tended to *silence the independent and discordant voices of those being represented* (1992:20) — that is, not all views are documented. Although such work has (usually) been motivated by intentions to better understand and show respect for Aboriginal culture, Cowlshaw argues that the outcome is much less laudable. She notes that anthropologists have generally preferred to focus on 'traditional' formations and largely sidestepped any critical examination of the colonial experience.



The concept of ‘culture’ has provided the key target for post-modernist scholars’ most telling critiques of the anthropological endeavour. Theoretical developments specifying the contingent nature of knowledge have exposed the processes through which the observer constructs a representation or interpretation of culture. Instead of the ‘neutral reporter’, the observer/anthropologist/commentator becomes the primary ‘creator’ of the ‘culture’ that becomes the subject of later scholarly review. This is not to say that culture does not exist but that its description and analysis is a highly *interpretive* undertaking that cannot be excised from the social, political and historical relationships existing between ‘observer’ and ‘observed’ (Layton 1997:184ff).

But the anthropological literature — including the Australian literature — has long since shifted its focus away from further developing the construct ‘culture’. Some have indeed speculated whether the concept has *exhausted its potentialities* (Pasquinelli 1996:63)

It is important to point out here that ‘culture’ is rarely invoked as a critical variable in relation to the health of Anglo-Australians. This is symptomatic of some of the problems arising within a culture-centred analytical framework. The notion of ‘culture’ is (mis)understood as a meaningful attribute *only of those who are different*, rather than as an attribute of all.

The concern for health services (and others) to respond to diversity has led to an interest in documenting specific cultural attributes of various populations. In an insightful critique of this approach Gunaratnam (1997) identifies three key problems:

- reification/objectification¹ of cultural and religious practices
- reductionism²
- failure to address professional and structural power relations.

1 The process of reification or objectification refers to conceptualizations of culture as ‘*thing-like, identifiable and observable as stable, bounded wholes*’ (Harris 1996)

2 Describing a complex phenomenon in terms of only one or other of its aspects or dimensions

A cultural 'factfile' is typified by *the cataloguing of largely descriptive information on the cultural and religious practices of different Black and ethnic minority populations*. Although seen as platforms of staff training and compiled with an intention to sensitise the workforce to difference, Gunaratnam argues that, on the contrary, 'factfiles' reify and essentialise cultural realities in ways that may constrain professional practice such that — paradoxically — they confirm as well as legitimate, discriminatory processes. 'Culture' is reduced to a list of points of difference, and individuals are imagined as having predictable responses accordingly. She further contends that such an approach reinforces an unhelpful professional discourse of getting it 'right' or 'wrong' by misrepresenting cultural processes as rigid, uncontested and unchanging.

There is an acute awareness that the processes of reification and codification of culture by either commentators and/or members of social groups themselves fail to capture or account for the openness, indeterminacy, and contested nature of social life (Harris 1996:10) — what Gunaratnam terms the 'unruly nature of cultural processes' (1997:173). Speaking of the palliative care health literature in the UK, she argues (1997:170) that cultural profiling exercises:

'... present a framework in which the cultures of Black and ethnic minority people are constructed as fixed and free standing. That is, as having an existence sui generis, rather than being seen as highly contingent, negotiated and unstable social projects.'

1.3 Cultural racism

The volume *Race Matters* by Cowlishaw and Morris (1997) provides key readings on racism in the context of contemporary Aboriginal Australia, including case studies of institutional racism in the context of health (Anderson 1997). In their article in this volume, 'Cultural racism' they argue that a concentration on notions of 'culture' — particularly conceptualised as an essentialised 'outer' pattern of social practice unrelated to the social, economic and political histories of its participants — may constitute a version of racism. ('Race' here is understood as primarily a social, not a biological category). Reducing culture in this way to a series of observable attributes (language, residence, foods et cetera) underpins a related idea that individuals or groups can have more, less, or even no culture according to how many of the agreed items one can allocate to them. In the Australian setting, a concentration on describing Indigenous Australian cultures shifts the analysis away from either a consideration of the impact and effect of a colonial history on particular populations, or the social and personal history of individuals and their families.



Thus Cowlshaw and Morris argue (1997:6) that the:

'... current appeal to 'culture' in defining Aboriginality turns out to be not so different from the explicitly racial definitions of an earlier era.'

Campbell et al (2000) — among others — caution against the tendency, in the discourse of diversity, to lay all explanation of difference in client response at the door of culture. And they remind that the institutional culture is of equal — if not greater — significance in shaping the responses of all parties. They point to education, gender, personal histories, socio-economic status and length of residence in the area as equally important influences on responses and interactional considerations.

1.4 Cultural safety

Ramsden, a key proponent of the concept of 'cultural safety', provides a detailed argument and description of the meaning and application of that term, including her reflections on what she sees as the gradual distortion of the concept from its original meaning (2002). She gives the key objectives of cultural safety education as educating practitioners (originally nurses and midwives) so that they:

- do not blame the victims of historical process for their current plights
- examine their own realities and the attitudes they bring to each new person they encounter in their practice
- are open minded and flexible in their attitudes toward people who are different from themselves, to whom they offer and deliver service. (Ramsden 2002:ch6)

Most importantly, she emphasises that it is the *recipients of the service, not the providers* who properly define the measures of whether or not a practitioner achieves culturally safe practice.

In Ramsden's formulation, the concept of 'cultural safety' is much less to do with culture — particularly in the sense of its description in Section 1.2 — than it is with establishing safe practice in relation to negotiating social diversity in health care settings. Indeed Ramsden states categorically in the following terms:

'It is clear that cultural safety does not place an emphasis on sensitivity or an awareness of other cultures. Cultural sensitivity and transcultural nursing are both concerned with having knowledge about ethnic diversity. This seems to be the basis of misinterpretation of the concept of cultural safety. The term 'culture' is read as 'ethnicity'. But the skill for nurses does not lie in knowing the customs or even the health related beliefs of ethno-specific groups. The step before that lies in the professional acquisition of trust.

Its emphasis is to place an obligation on the nurses to provide care within the framework of recognising and respecting the difference of any individual. Rather than the nurse determining what is culturally safe, it is consumers or patients who decide whether they feel safe with the care that has been given, that trust has been established, and that difference between the patient, the nurse and the institutions which underpin them, can then be identified and negotiated.' (Ramsden 2002: ch10)

The formulation of culture underpinning this concept is broad. It is explicitly inclusive of attitudes, relationships of dominance, personal histories, and institutional arrangements. It puts the onus of reflection and interpretation on practitioners and the role of measuring success on the client group.

Koori writers on the meaning of 'cultural safety' emphasise the affective component, for example, describing it in terms of clients needing to 'feel safe to act and express themselves in a Koori way' (Clarke et al nd:76), or to feel 'culturally affirmed'. Importantly their 'golden key' to achieving cultural safety is also envisaged in terms of personal sensibilities – the qualities of being 'receptive, open, understanding and warm to cultural diversity' (Clarke et al nd). This volume by the Aboriginal Family Support Unit Workers from the Melbourne Children's Hospital uses short illustrative case examples taken from their hospital experiences as their primary means of instruction.



1.5 Values and ethics

Having an appreciation of the different values that people may attach to health and health services is critical if practitioners (and others) are to engage productively with socially and culturally diverse clients. Key ethical principles such as informed consent, confidentiality, notions of risk, harm and benefit are all underpinned by values concerning the rights and obligations of the individual, preferred forms of decision-making, understandings of social versus personal responsibility, frameworks for assessing risk and harm and so on. Such values are socially and culturally constructed. Further complications arise where there is no shared language between parties.

In relation to Indigenous Australians there is a growing literature on ethical engagement and informed consent (McAuley et al 2002, Humphery 2000, 2001, Anderson 1996, Casteel 1998). This literature has emerged from both Australian and international work with Indigenous groups and so is particularly informative. While much of it refers directly to participation in research, the considerations of ethical principles — particularly informed consent, autonomy, consultation processes and so on — are detailed and provide a good basis for extracting Practice Principles for ethical considerations in cross-cultural palliative care. The literature suggests there may be considerable difference in values relating to:

- the rights of the individual/family/community
- notions of public/private life
- notions of harm/benefit
- informed consent and decision-making.

Campbell et al (2000) provide a useful outline of the key ethical issues that are likely to arise, particularly in relation to communication on the subject of death and dying and in the provision of palliative care. They identify and discuss four 'critical' areas (2000:71) in relation to working with clients of diverse cultural backgrounds including:

- communication and the use of interpreters
- language and key terms
- disclosure
- consent.

1.6 Reflective practice

'Reflective practice' is an approach articulated most clearly in the Australian context in the social work profession, in a series of key papers by Jan Fook (1996a, b, 2000). Reflective practice is a process by which practitioners extend and refine their practice through a systematic and regular process of critically appraising their own professional practice.

This approach emerged from a socially engaged practice in a profession where encounters are (often) volatile, unpredictable and uncontrollable (Fook 1996:4) but which require on-going negotiation and analysis. The approach supports an analysis based on the specific context of any particular situation/event, with a recognition that the full context — and therefore its analysis — will include *'different and possibly competing perspectives'* (Fook 1996:4). Describing this approach as one that affirms the value of the experiential, the interpretive and the intuitive in building knowledge (and skills), Fook contrasts it with the strongly positivist paradigms with their emphasis on measurable, objective phenomena. Most useful, however, is a brief description (Fook 1996) of how a practitioner and their colleagues might undertake a reflective practice session. Essentially it entails a careful and critical review of a situation, a program or an incident from several directions.

For example, it asks the practitioner to differentiate thoughts, feeling, actions, intentions and interpretations; it probes the assumptions that underlie these positions and encourages the practitioner to identify their origins; it asks participants to look at the kinds of language used, including 'key and recurring terms' and so on. Reflective practice can be used as a group or an individual activity, as a formal educative process or as a self-reflection tool. It is flexible and productive in a wide range of professional settings. Undertaken skilfully it could be particularly productive for a professional team comprising professionals of different cultural backgrounds. It offers a process through which concepts of cultural safety might also be introduced as well as developed.



1.7 Frequency of experience of death

There is ample evidence that Indigenous Australians are experiencing deaths of family members and kin at rates far beyond that of other groups in the population. Death is from disease, violence and despair; it happens in homes, hospitals, prisons and on the streets. The statistics (Appendix 2) make clear the gravity of the situation as well as the extent of the disparity between rates and types of Indigenous Australian deaths and those of the broader community (Kellehear and Anderson 1997). The lived experience for those communities is what Weeramanthi (1995) has termed ‘chronic grief’ as individuals and families repeatedly deal with the deaths of loved ones. The situation was described graphically by a Centralian woman as ‘having sorrows nearly every year (because) for Aboriginal people, the young and the old are dying (Devitt and McMasters 1998:166).

The stress associated with this too-frequent death extends in a ripple effect into the health services sector where Indigenous Australian health professionals are further exposed to the situation. The need to somehow find professional distance in the face of recurring personal sadness is a constant feature of the workplace for many Indigenous Australians. As May Rosas, the then Community Health Educator at Wurli-Wurlinjang Aboriginal Health Service in Katherine (NT) told Weeramanthi:

‘... we’re not dealing with clients, they’re our families and friends ... deaths are spiritual and social events for us primarily, but we do need also to think of them as health events ... we need to share our different knowledges so our people can see both sides.’ (1995:246)

The grief associated with too-frequent death is occurring within families and communities where — in many cases — there has also been a long history of trauma, death and family destruction over several generations (cf *Bringing them Home* Report 1997).

1.8 Relevant findings from key palliative care reports

Sullivan and Associates (2003) provide a comprehensive review of four major reports concerning palliative care services for specific Aboriginal and Torres Strait Islander populations including:

- *'Let me Die in My Country': Palliative Care Needs of Aboriginal People in the Kimberley and Pilbara Regions of Western Australia*, (1996) by P Williamson, Final Report North West Aboriginal Health Strategies Unit. Broome.
- *Appropriate Care: The Palliative Care Needs of Victorian Aboriginal People*, (1997) by P Wagstaff, Draft Report for the Victorian Department of Human Services.
- *The Terminally Ill Koori: Their Care and their Carers*, (1997) by O Collis-McAnespie, P Hemmings, L Bell and A Dawes, Australian Rural Health Institute, Charles Sturt University, Albury.
- *Developing an Aboriginal Palliative Care Strategy for South Australia*, (1998) by EA Bourke, EA and R Mobbs, Aboriginal Research Institute, University of South Australia, Adelaide.

They drew a lengthy list of significant issues – not ranked in any priority or order – from each of these reports. From that data we compiled the following consolidated, thematically arranged set of issues:

An Indigenous Australian context?

- no unitary 'Indigenous Australian experience' of palliative care
- cannot generalise across Indigenous Australian communities concerning culturally-based responses, including to matters of spirituality
- profound cultural dissonance between Indigenous Australian and non-Indigenous beliefs concerning health, which is most pronounced in relation to death/dying
- influence on the health of Indigenous Australians of the history of racism, including regulation on movement, inadequate access to services and poverty.



Level of understanding

- concept of palliation and existence of services of palliative care neither understood nor well known
- need for culturally appropriate information for patients/clients, families
- need for strategies to assist Indigenous Australian health professionals, community agencies, families and communities to understand the place of palliative care in health.

Services/systems aspects

- need to decentralise palliative care services beyond hospital contexts. Evacuation from home communities to distant facilities (hospital/hospice/residential care) is fraught with serious disadvantage for achieving a 'good death'; fear of eventual death/burial outside of home area leading to individuals avoiding health services
- difficulty of some (non-Indigenous Australian) health professionals ('doctors' specified) conceding their lack of 'expert' authority in relation to Indigenous Australian knowledge including preferred options and appropriate processes for palliative care
- majority of Indigenous Australian deaths in communities are not associated with old age; death is more likely to be unexpected and accompanied (often) by unresolved grief
- communication difficulties between hospitals and families concerning impending death of relatives
- majority of those with terminal illnesses are not elderly – approaches through aged care and palliative care are distinctly different.

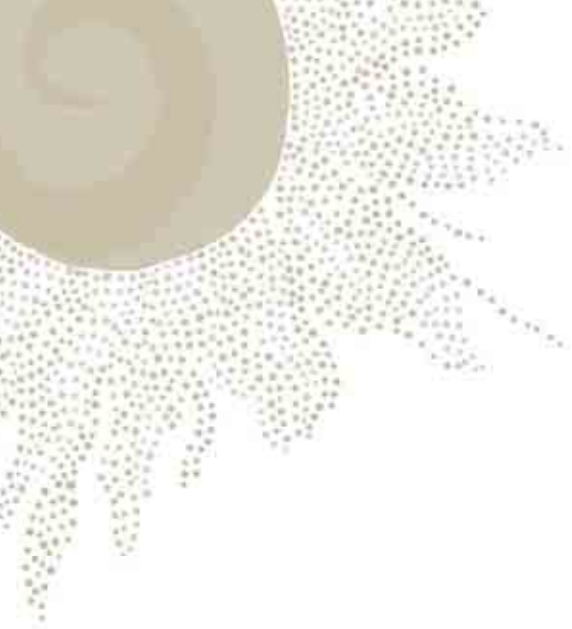
Developing culturally responsive programs for Aboriginal and Torres Strait Islander communities

- effective processes will be built on Indigenous Australian control and/or significant decision-making involvement
- need to develop meaningful partnerships with local Indigenous Australian service networks including ACCHOs, regional Indigenous Australian networks and disability networks
- significance of concept of 'community' including recognising the diversity and autonomy of the range of 'community' groups that exist
- Indigenous Australian elders play an important advisory role
- significant role for traditional healers.

Central role of the family

- consideration of problems associated with community-based care in communities suffering high levels of social problems (security issues, stress, et cetera)
- severe levels of stress experienced by families supporting and managing the needs of a dying relative — patient and families often not adequately briefed; carers lack emotional support and experience financial hardships
- strong theme of self-reliance; families preferring to keep care ‘within the family’ for as long as possible. ‘This was seen to decrease potential conflict with non-indigenous health providers, particularly in hospital settings.’ (Sullivan and Associates 2002)
- particular difficulties associated with hospital settings.





2 Literature review

2.1 Some features of the literature on death and dying

2.1.1 Contours of the literature

There is vast amount of primary historical and ethnographic material detailing aspects of death and dying in Indigenous Australian cultures. Based on first-hand observation, these sources range from particularly detailed contemporary accounts (some in more than one medium) of the funeral ceremonies of one or two specific groups (Morphy 1984a, Dunlop 1979, Levy 1975, MacDougall 1977, Williams 1989), to an extended analysis of social change through practices associated with death (Fitzpatrick-Nietschmann 1978, 1980), and early observations of practices that have long ceased (cf Spencer 1964, Howitt 1904, Spencer and Gillen 1969 (1899)). Nevertheless, Morphy (1984a:127) argued that, with the exception of the Yolngu of northeast Arnhem land, Australianist anthropology has not investigated mortuary rituals and burial practices with any depth.

As well as being of variable quality, reflective of the skills of the authors, much of the literature has only marginal relevance to either views concerning death and dying or to palliative care for contemporary communities. The historical literature in particular (but not only) may contain material — text and images — that is offensive as well as irrelevant. Much of it is not readily accessible except through special collections.

The ethnographic literature — by definition — has a concern with the particularities of place/people/time that limits its application outside the timeframe or community of observation. Having said that however, good ethnography (cf Reid 1983, Myers 1986, Merlan 1998) is always more than a checklist of ‘customs’. An analytic reading should produce insights into key values as well as the nature of the underlying explanatory frameworks and/or social processes and institutions that tend to persist through time despite observed variability.



There is also an ever-growing 'derivative' literature — sometimes called 'secondary' source material — which summarises available knowledge. This ranges from useful generalist introductory books (Edwards 1987, 1988, Bourke et al 1994), to more specialist in-depth compilations which may well incorporate the author's specific local experience (cf Elkin 1974, Berndt 1988), to those providing a level of meta-analysis (cf Swain 1993, Eliade 1973). Cowan's series (1992, 1993, 2001, 2002) which deals extensively with cosmology, spirituality, mythology, psychic worlds and so on represents a particularly popular strand of literature. His themes are contemporary (in the sense of their appeal to an audience interested in religion, spirituality and/or the 'new age') and the source material, largely scholarly. Nevertheless, despite appropriate acknowledgement of the regional origins of particular rituals, practices, beliefs, et cetera, the overall presentation is of a generalised unitary worldview held by 'the Aborigines' living in some, timeless traditional moment. Acknowledging the 'introductory' quality of these sources, and possible value for study, they have limited value in contextualising contemporary Indigenous Australian life. In particular, they may reinforce a 'cultural' deficit analysis of contemporary groups.

Additionally, there is an expanding health sciences literature concerning this subject (see above and for example, Kellehear and Anderson 1997, Willis 1999) and a rapidly growing stream emerging from palliative care practitioners themselves (Fried 1999, 2000, 2003a & b; Prior 1997, 1999, 2001, McNamara et al 1997). This primary source material includes literature that draws on concepts, theory and methods of the social sciences, but also includes a range of (usually) one-off accounts that report on specific cultural factors (Wake et al 1999). These vary from the insightful to over-generalised reports of local experience.

There is now also a multitude of Internet sources of information. These have not been reviewed (a thorough review being beyond the scope of this review) but they should be used with the standard cautions attached to Internet information – checking of dates, authors and sources.

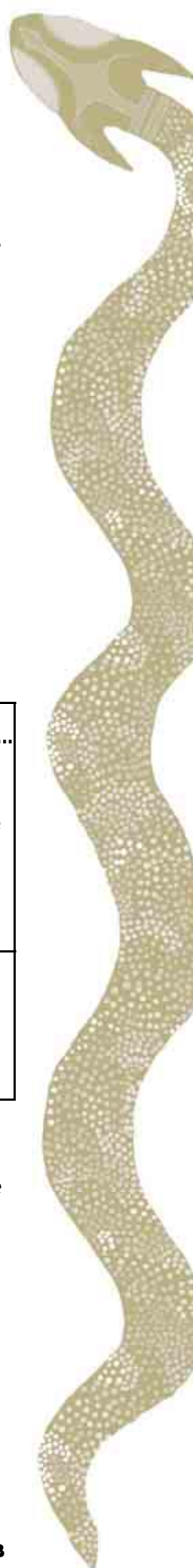
2.1.2 Social and public emphasis

With notable exceptions, the Australian anthropological literature — as elsewhere (Hockey 2001:21) — concentrates on the collective, public and ritual aspects of social practices associated with death and dying. Individual, personal and emotional experience are little reported. Reid’s (1979) consideration of grief and mourning among Yolngu people and Berndt’s (1950) early reflections on several women’s personal expressions of grief through song are among the few exceptions noted.

The range of issues in chapters on ‘death’ presented by Elkin (1974) and Berndt (1988) — perhaps the two most cited of the generalist summary sources — provides a sense of the coverage of this topic in the Australian ethnographic literature to that point. The concentration on the public, collective and ritualised is clear.

Author	Chapter	Contents
Elkin	Death and what follows (Ch XIII)	Death, Inquest and Revenge; Death, a social event, Customs associated with dying and death; The inquest and its forms; The spirit and the corpse; Divination and control; Revenge and social duty Burial Rites, Social status and burial, The meaning of the ceremonies, The fate of the dead, The cycle of life
Berndt RM and CH	Death and the after-life (Ch XIII)	Some social implications of death, Disposal of the corpse — desiccation, interment and/or reburial, platform and tree disposal, cremation, other forms of disposal, cannibalism; The ritual of death; Inquest; Comment; Land of the Dead; Transition.

The anthropologist Joe Reser (1990) remarked that the importance of the affective dimension of interpersonal relations is both little studied — particularly in non-Western settings — as well as being highly important to Aboriginal people where he notes (1990:182) the significance of ‘showing the proper feeling’ in Aboriginal social settings. Davidson (2000) argues that understanding the significance of this difference between Indigenous Australians and Anglo-Australians is critical for effective intercultural communication.



Speaking of the Pintupi, Myers (1986:103) suggests that within the established extended kinship relationships, the dimension of 'affective relationships' or emotionality is the key emphasis of the Pintupi themselves in day-to-day social life. He comments that:

'What order and cooperation existed in these low-population-density groups depended largely on the ties of recognised relatedness and their emotional considerations. The discourse of daily life is heavily nuanced with expressions and demonstrations of such emotions as 'compassion', 'melancholy', 'grief', 'happiness', and 'shame'.'

Nevertheless, the literature has little to say about such emotion and its expressions, or the private and personal, in Indigenous Australian communities. An exception to this is the extended account of a particular death and its aftermath on the Tiwi Islands (Venbrux 1995).

While still an underdeveloped literature overall, the contemporary social health literature, particularly mental health, addresses aspects of grief and its expression in Indigenous Australian contexts. Key resources in this field include Swan and Raphael (1995), *'Bringing Them Home'* report (1997), Hunter (1993b) and Dudgeon et al (2000). In each case these volumes are as valuable for their bibliographic resources as for their arguments and conclusions. In the case of large enquiries and/or national projects such as Swan and Raphael (1995), the associated reports are likely to contain significant additional data on particular topics.

2.1.3 Concentration on 'traditional' groups

Indigenous Australian people in settled Australia (generally southern/eastern and urban Australia) have a cultural identity that is both distinctive and strongly continuous with that of other Indigenous Australians from those areas where intrusion and dislocation was both on a lesser scale and more recent (Keen 1994). While the lifestyles of Indigenous Australians — ostensibly — may be indistinguishable from other Australians of similar socio-economic status, social formations (including social relations, attitudes, values, beliefs, and practices) continue to underpin the reproduction of a distinctive identity (Eckermann 1977). The social and cultural transformations effected through the colonial experience (which itself varied regionally) are complex and may include not only destructive and fracturing influences on social life but also the intensification, reinforcement and elaboration of certain aspects of 'traditional' social life — for example, the

effect of poverty as a pressure reinforcing extensive kin-based networks (Gale 1977) or an increasing social emphasis on attendance at funerals³. Shannon (1994) argues that whilst Aboriginal culture may be described as ‘non-traditional’ by some ‘*it is also very non-white Australian*’ and she identifies the principal common characteristics as being: close kinship bonds, an emphasis on sharing and generosity, as well as on communal living and decision-making (1994:34).

The literature — particularly the ethnographic sources — concentrates largely on the northern and/or remote half of the continent. There is no comparable literature for the south-eastern third of Australia which was settled much earlier. This is not to say there is no literature, however it tends to be historical, fragmented in character, often documenting events and practices not current at the time of writing, or reconstructions based on a diversity of early sources (cf Berndt 1993, Bell 1998).

Christianity had — and continues to have — a profound impact on Indigenous Australian peoples and cultures. Swain and Rose (1988), Swain (1998), Charlesworth et al (1984) and Charlesworth (1998) are key sources. While the effects of Christianity are most apparent in local responses to death and dying, there is limited analysis, particularly around the central issue of death and the spirit or soul (although see Morphy 1984a & b, Fitzpatrick-Nietschmann 1978, 1980). The majority of Aboriginal people, including those whose lives have been intensively documented, are now all adherents of one (or more) of a wide range of Christian faiths (Lee and Daly 1999). In the Torres Strait there are also a number of adherents of Islam. The alternative spiritual and philosophical views of Christianity have been differentially taken up and woven into the fabric of Indigenous Australian beliefs and practices (cf Bos 1988). The process of untangling Christianity from its colonial and non-Indigenous cultural matrix is also proceeding. See for example, the volume *Rainbow Spirit Theology* (1997) which presents a theological statement by a group of Aboriginal Christian elders concerning this process and its potential.

³ Ian Anderson – pers comm 2003



Fitzpatrick-Nietschmann (1978, 1980) provides one of the few studies of contemporary (Christian) social practices associated with death in her analysis of the cultural transformation on Mabuiag Island in the Torres Strait. She examined Tombstone Openings as ritual and as a case study of ‘dynamic socio-cultural change’ (1978:1). A Torres Strait Islander, Lui (1988) has also undertaken research associated with Tombstone Opening in the Torres Strait⁴.

A consequence of this limitation is that in a review such as this the imbalance tends to be reproduced, as examples are primarily drawn from those areas for which the literature is richest and most recent — for example, the northern and western areas.

2.1.4 Scarcity of Aboriginal and Torres Strait islander voices

Indigenous Australians recall personal experiences of grief and loss, as well as death, in a raft of published biographies (cf Barker 1977, Langford 1988, Morgan 1987, 1989). These personal stories are perhaps most prolific in the documents associated with several government enquiries (for example, Stolen Generations, Royal Commission into Aboriginal Deaths in Custody, land claims, native title claims, trials). Additionally, most major state libraries/archives and many universities hold collections of local accounts. The largest single collection is probably that of the Australian Institute for Aboriginal and Torres Strait Islander Studies. To this point, there has been limited further analysis and interpretation of that considerable material.

Few Indigenous Australian authors have directly addressed the social understandings of death/dying, although some multi-author publications on this specific subject include Aboriginal co-authors (cf Wake 1999). Indigenous Australian authors have more frequently approached this subject in the course of other kinds of commentary and research — for example, in relation to the deaths in custody of Indigenous Australians (Langton 1990) or in relation to the on-going consequences of the historical violations of the dead in Tasmania (Lehman 1996). There is also a rapidly growing corpus of health literature (including mental health) investigating aspects of death (Cunningham and Paradies 2000, Swan 1998).

4 Unfortunately we are unable to provide further information from this source as we sighted it late in the review process and so were unable to complete the necessary permission for citation within our timeframe

Is this a problem? It may be if the published texts — in which, as Nakata (1995) asserted in reference to Torres Strait Islanders, ‘we are only ever represented within the terms of the particular discipline of the particular expert’ — continue to be understood as the single most authoritative form of ‘evidence’ for all aspects of health development and service provision.

2.1.5 Imbalance of geographic coverage

The literature shows an imbalance of coverage with respect to geography for reasons outlined under 2.1.3 above. The richest documentation covers a limited extent of Australia — largely the northern and more remote areas. This relates to the impact of colonialism on the one hand and on the other — in the case of ethnographic coverage — the strong influence of ‘traditional’ anthropological concerns with kinship, ritual and social organisation on the direction of disciplinary research (Cowlshaw 1992). The more northern and more remote regions were — and some would argue remain — preferred locations for research. Within this northern bias, there are also micro level imbalances. There are regions with long histories of multiple research effort, for example, the Yolngu, the Tiwi or the Pintupi of the Northern Territory, and others with virtually no literature profile.

2.2 Key themes in the literature

In the sections that follow we briefly sketch the key themes evident in the literature that considers death and dying. These themes are also selected on the basis that they are relevant to provision of palliative care. This approach provides only a basic and perhaps historical context. We emphasise that the most pertinent information is contained in the reports and papers that have recently surveyed Indigenous Australian community opinion *specifically concerning palliative care and the issues that arise for families dealing with terminal illness and death*. The research of Sullivan et al (2003) who undertook national consultations on the issue of palliative care, supersedes most of the literature reviewed below: it is contemporary, it has sought out the views of Indigenous Australians as well as agencies and maintained a consistent research focus on understanding the key palliative care issues experienced ‘on the ground’. It is a key resource. What is unfortunately not available for much of the country is any local or regional contextualising material to complement that survey. This section of the literature review can be seen as a preliminary effort to augment that more current work.



2.2.1 Historical responses: accommodation, incorporation and rejection

While the impacts of British colonialism were cataclysmic and destructive, social and cultural change prior to this period had taken place through less disruptive processes. Incorporation, accommodation and adaptation had been on-going throughout Australia and the Torres Strait through local interactions between similar neighbouring groups as well as interaction with those of quite different cultures. The most remarked on of these is the Macassans interactions with northern Indigenous Australian groups (McKnight 1976), but the Torres Strait Islands with their proximity to New Guinea as well as Australia represented a continuous path of social and cultural exchange. Equally, within the continent, cultural formations such as social classification systems as well as particular ceremonial complexes are known to have been adopted gradually over expanding areas of country.

Indigenous Australian responses to the social mores and practices of the colonists, including those associated with death, reflect processes of accommodation and incorporation, as well as rejection and opposition. Perhaps the most significant single influence has been the adoption of Christianity by the majority of Indigenous Australians such that today around 72 per cent of Indigenous Australians report themselves as being Christian. Of those, around 50 per cent are either Anglican (25 per cent) or Catholic (24 per cent)⁵. Consistent with the reported trends though, there is only sparse literature on the understanding of death and dying within an Aboriginal Christian framework (but see Lui 1988, Fitzpatrick-Neitschman 1978, 1980). Interestingly this is true also for the Tiwi people of Melville and Bathurst Islands where elaborate mourning and burial business comprises the central ceremonial and ritual life of the Islands. Despite an intense — culturally speaking — Catholic missionary presence on the islands since just after the turn of the century, the most cited scholarly accounts of the Tiwi from the 1950s to the 1980s (Hart and Pilling 1960, Hart et al 1988, Goodale 1974) virtually ignore the effects of long-standing religious change. This omission in ethnographic reportage is common and has the effect of amplifying the bias towards ‘tradition’ while simultaneously ignoring the processes of modernisation and change that are everywhere apparent.

⁵ 1996 Census of Population and Housing — Aboriginal and Torres Strait Islander People ABS catalogue no 2034 0 Australian Bureau of Statistic p75

In many areas, particularly in northern Australia, continuity with pre-Christian practice is apparent. Toussaint, speaking of the Kimberleys and noting the strong early influence of the fundamentalist United Aborigines Mission, explains that people do not see a necessarily strict demarcation between activities related to Indigenous Australian laws and those associated with Christian belief and worship — they are not seen as mutually exclusive. ‘Today many people consider themselves both ‘law-people’ and followers of Jesus Christ.’ (1999:341) Of the Pintupi, perhaps the most recent communities to have engaged fully with the colonisers, Myers (1999:350) notes that ‘the contemporary dynamism of cult life in the Western Desert develops side by side with Christian (mainly Lutheran) proselytism’.

The process of adaptation is one of communities and individuals extending and re-interpreting existing frameworks to incorporate new insights. Morphy (1984a:128) makes this point in relation to mortuary rituals in Arnhem land, suggesting they are a ‘dynamic institution’ and that it is this very dynamism and capacity to accommodate change that explains their persistence as key cultural events for contemporary Yolngu.

‘The models (concerning the nature of soul/s and the afterlife) set out the possibilities but leave room for agnosticism, as well as for the incorporation of new speculations’ (1984:41)

Magowan (2001) describes the re-interpretation of traditional symbols to incorporate Christian references in mourning songs of contemporary Yolngu women. Christian figures are considered as embedded in the landscape for contemporary Arrernte Christians (Morton 1999:333).

The Torres Strait Islands represent a case of an early, pervasive and remarkably swift religious transformation. In 1871 Christian missionaries of the London Missionary Society arrived to undertake mission work on Darnley Island. That event is still celebrated as the ‘Coming of the Light’ (Herle and Rouse 1998:9) and seen as an historical process that positively transformed Island life (Boigu Island Community Council 1991, Bani 1987). By 1879 the Society was training young Torres Strait Islanders for mission work in its Papuan Institute and had placed a teacher in each of the larger communities (Beckett 1998:36). Due to the remoteness of the Torres Strait from the Queensland administration, church officials often also acted as agents of the Queensland Government (Beckett 1998:36). The London Missionary Society employed a number of Pacific Islanders as teachers and pastors. These proved particularly powerful agents of change and their influence ‘transformed Torres Strait daily life’ (Beckett 1998:38). Twenty-five



years later, the Haddon Cambridge Ethnographic Expedition of 1898 was frequently engaged in documenting practices — including those associated with mortuary rites — which had entirely lapsed so thoroughgoing had been the change. The meaning of that rapid transition is being re-examined by contemporary Torres Strait Islanders (Mosby and Robinson 1998, Mosby 1998).

In parts of Australia, Christianity has become a recognised pathway through difficult social and personal issues. Hume (1988) describes the evolution of the ‘new’ Christianity in Yarrabah, Queensland and notes its potential for both revitalising the community and providing new avenues for dealing with contemporary issues. She also describes the opposition to this view by others and their rejection of the ‘born-again’.

In the south/south-east as in the north, commentators suggest that funeral rites and mourning practices demonstrate continuities with identifiably ‘Aboriginal’ values.

Calley (1955) describes the expansion and operation of a Pentecostal Christian movement among the Banjalang people of northern New South Wales. He suggests that the continuing importance of funerals within the Christian (Pentecostal) framework is itself ‘in keeping with’ the ‘old rule’ as it was described to him by local Banjalang Aboriginal people.

Flood (1985) provides a view of the merging of Kamilaroi understandings of death with Catholicism among Aboriginal people of the Moree area noting both continuities with past practice (gathering of a large number of kin through extended networks at funerals and associated social activities, the replacement of formal wailing with similarly ‘doleful’ hymns, the adoption of a standard — ritual — dress) as well as the incorporation of Catholic and other non-Aboriginal rituals — the sprinkling of dirt on the coffin, the wearing of all black and so on. Appointment as pall-bearer is seen as a (Koori) community honour (Clarke et al nd:72).

The outcome is a volatile mosaic of localised responses. The implication clearly is that issues arising from the care of the dying can only be understood in their contemporary local context.

2.2.2 Centrality of place

A recurring insistence by Indigenous Australians on the importance of acknowledging the 'localness' of cultural traditions and the specificity of regional patterns and ways of doing things (Sullivan and Associates 2003, Dudgeon et al 2000) is itself a pointer to the centrality of place in their lives. 'Place' here refers to particular geographic localities, either urban, rural or remote. It means home, homeland or one's own country. 'Own home country' is a central theme in relation to death because it (the specific country) is understood as the embodiment of the social, spiritual, personal and historical — including ancestral — dimensions of being. That is, it is intimately connected with relationships to the living (one's kin and family), to one's history (place of birth, living) and to one's spiritual identity (ancestral connections and forebears). It provides the underpinning framework of Aboriginal spirituality (Charlesworth 1998). The notion of 'own home country' is the leitmotif of life and is also central at the time of death.

Ideally, at the time of death, a person is on or near their home country with appropriate kin and family so that their spirit — in whatever form/s it is believed to exist — can freely move on to the next phase of its existence. There is a diversity of beliefs concerning the soul or spirit (see section 2.2.5). However, the importance of being in or near to one's own home country at the time of death is widely supported (Sullivan 2003, Ramanathan 1998, Willis 1999).

For some groups the spirits of the deceased are believed to travel on to a specific place — 'a country of the dead' where they then lead a parallel kind of existence to that being enjoyed by their kin here on earth, except that it is in another realm or dimension (Berndt and Berndt 1964:412). The Mabuig Islanders of the Torres Strait know the place as Kibu (Fitzpatrick-Nietschmann 1980:171), the Goulburn Islanders know it as Ulurumbu or the Unknown Island (Lamilami 1974:40), people of Carnarvon in Western Australia described it to Gray (1976:147) as a deep cave in limestone country in a neighbouring area. For Yolngu, the country of the dead is regulated by the same Yirritja/Dhuwa relationships as is social life here on earth. In a detailed description of a particular funeral in Arnhem Land, Morphy (1984) provides an analysis that centres on the relationships between the deceased, their kin and their country. He demonstrates how the funeral rites reflect all the deceased's particular personal constellation of affiliations including to kin, clans, country and ancestral beings.



However, in some areas the actual place at which a person dies — the house, or camping place — becomes subject to a number of restrictions, including non-residence. Family and kin may need to move away for sometimes lengthy periods (months to years) from the location of death (Berndt 1988). Smoking or similar activity is a common method of clearing or ‘opening’ an area. In other areas family and kin may need to wait for a seasonal cleansing cycle of rain. Belongings of the deceased may be burnt or otherwise disposed of. A gathering of extended family and kin may be required at or near the deceased’s home country (or at a location determined by the family) for periods of days, weeks or longer depending on the burial ceremonies and the relationship to the deceased.

2.2.3 Kin and family

Kin and family play a pre-eminent role in Aboriginal and Torres Strait Islander social life (Shanon 1994, Keen 1994, Gale 1977, Clarke et al nd, Berndt 1988, Myers 1986).

Although there are regional variations, kin assemble near a relative known to be dying or one who has recently died. In the Sandover region of Central Australia, local people preferred medical practitioners to clearly indicate the likelihood of death of a relative as family and other kin often travelled to make what they surmised would be a last visit to an individual known to be seriously ill, particularly if they were being evacuated to hospital. Speaking of contemporary Tiwi, Venbrux notes that relatives may stay with the spouse of the deceased in the event of violent or otherwise unexpected deaths and in circumstances where the spouse is felt to be vulnerable (1995:66). Goodale (1971) provides several detailed accounts of activities following deaths on the Tiwi Islands including an analysis of associated rituals.

Particular kin may have responsibility for announcing or advising of a death (Fitzpatrick-Nietschmann 1978, Morphy 1984a) and precipitating the appropriate mourning rituals which will usually include formal wailing, sometimes accompanied by self-inflicted wounds. Not surprisingly, the nature of the death — whether peaceful, expected, violent, et cetera — will significantly determine the course of events and the intensity of responses.

Hiatt provides notes on the formal roles played by various kin for a text by Gurmanamana on death the Anbara way (Hiatt et al 2002:160).

'An older brother decides on the method of disposal. Sister's sons supervise the autopsy, take charge of purification rituals, distribute their uncle's belongings for burning, and contemplate vengeance. Joking partners⁶ carry out the autopsy and also contemplate vengeance. The widow mourns and tells the nephews she has been a good wife.'

Everywhere there is an expectation that kin — including extended families — will make considerable efforts to attend the rites associated with death, mourning, funerals and burial. (Gray 1976:150, Calley 1955:13 part III). The notion of 'kin' within Indigenous Australian communities is broad and this will generally mean the involvement of large numbers of people.

There are considerable regional differences in the relative focus on mourning activities, funeral rites and final burial. For example, in Central Australian regions the focus of social attention may be much more on the mourning assemblies than on the actual burial rites (Meggit 1962). In the Sandover Region, (non-Christian) burial occurs as soon as practicable after a death and involves a small group of designated kin only — it is not a public affair. The gathering of relatives at what is usually termed the 'Sorry Camp' is the forum for social and public as well as private grieving, in addition to being the arena for ceremonies associated with death⁷.

Sorry Camps — or their equivalent — are a well-recognised aspect of public mourning. Close family may reside in the 'Sorry Camp' for periods of days, to weeks, to months depending on the local practice. Other relatives and kin may reside there for longer or shorter periods depending on their particular circumstances. Where specific Sorry Camps are not established — as in more urban areas — relatives may stay for extended periods either with the grieving family or in a nearby location.

There are common forms of public grieving and mourning used to greater or lesser degrees in different regions of Australia, including the gathering together of kin, weeping, wailing and keening, holding each other, gashing scalps and tossing ashes and dirt over themselves. Specific female kin may cut their hair off; there may be almost continuous public wailing. Reid (1979:41) describes the features of Yolngu mourning as being:

6 A specific classificatory relative, Hiatt et al 2002:33

7 Information based on accounts from people of the area while a resident there (JD)



- ritually structured, confined in time/place
- expected; collectively and publicly expressed
- interwoven with demands/activities of daily life.

She observed also that anger and aggression are channelled and controlled, and that there is a socially defined limit to 'normal' grief.

At the time of a death certain categories of relations — including spouses, siblings, in-laws and children — may be required to observe special regulations. These may include restrictions on communications with others, on diet, movement (avoidance of places, et cetera), clothing and body decoration or any combinations of these. It is commonplace in some communities for family and kin to paint themselves with ochres in specific designs, or simply cover themselves liberally (cf Morphy 1984a). In some cases the house, the vehicle, and other areas in the community used by the deceased may also be marked with ochre. There are conventions regulating both the time and the manner in which these kinds of markings including body markings may be removed.

In many places there are also a series of rituals — including the actual burial — associated with a death. Goodale (1971:271) notes for the Tiwi of Melville Island that a (variable) period of some months might elapse before the final elaborate Pukamani ceremony is held to mark the conclusion of the mortuary rites. Similarly in other places there may be a series of sequenced rituals managed by family. In the Tombstone Opening ceremonies of the Torres Strait there may be several years between the actual burial and the conclusion of family business associated with the death. Described as the 'last farewell' for the deceased, the ceremony centres on the unveiling of a tombstone at the gravesite. Fitzpatrick-Nietschmann (1978, 1980) details one such sequence on Mabiliaug Island. The Tombstone Opening event marks the conclusion of mourning and is accompanied by extensive gift-giving between particular sets of kin, feasting and final visitations to the elaborately decorated gravesite with its new headstone. Although an innovation of a hundred or so years ago, the Tombstone Opening emphasises continuity as well as cultural identity through its emphasis on fulfilment of social obligations, honour and respect for the deceased. Increasingly though, it is a time of some tensions as networks of kin seek to accumulate sufficient money to properly discharge their obligations of gift-giving as well as meet expenses associated with hosting such an occasion. Fitzpatrick-Nietschmann (1978) observes that economic pressures have resulted in extension of the period before a tombstone is finally placed from around 12 months to sometimes several years.

2.2.4 Continuity: life–death–life

Within Indigenous Australian religious frameworks, individuals are understood to be fundamentally ‘spiritual’ beings (Eliade 1973:84). Morphy (1984a:15) speaks of the Yolngu having a ‘spiritual continuity’ between the present and the ‘Ancestral Past’ through the dense network of relationships — personal, social, ecological, spiritual — that exist in the present but have emerged from the ancestral past: ‘in these and other ways the cosmic order is projected into the everyday world’ (Morphy 1984c:215).

The notion of a ‘continuity’ or a ‘cycle’ encompassing life and death is widely reported. Elkin (1974:361) speaks of the ‘cycle’ of life wherein a person moves from the realm of the spiritual through to the profane/mundane life at birth and, at death, re-enters the spiritual realm.

Berndt and Berndt (1981:476) propose a continuity of ‘life’ (after death) where spirits live somewhat similarly to the life here on earth, but in a different ‘realm’ or space’. The places where the spirits of the dead (or some component of their spirit) go are taken to be locations comparable to those on this earth. The elaborate rituals associated with death mark a transition point for the individual but also confirm the on-going relations between the living. The loss of personal distinctiveness, or the separation caused by death is not viewed as annihilation of the spirit (1985:486) and thus Berndt and Berndt suggest that the underlying logic of mortuary ceremonies is not a ‘pre-occupation with death but an emphasis on life’ (1985:478). Similarly, speaking of the Torres Strait tombstone opening ceremonies Fitzpatrick-Nietschmann (1978, 1980) interprets the ceremonies as marking a transition — not an end. Willis (1999) frames a similar view differently, arguing that dying (for the Pitjantjatjara) is best understood as a culturally mediated aspect of a specific way of living, and is inter-related with other aspects of the particularities of that way of living.

(McDonald 2001:21) in her recent Kimberleys-based work, concurs with Morphy that the idea of a ‘flow’ of energy or a life-force that flows through the living and returns cyclically with the dead to the ancestral realm has strong resonances. She links that principle to understandings of health and illness in which the life energy or life-force is thought to also flow around and throughout the body.

The cycle expressed as ‘life–death–life’ has wide contemporary currency. For example, it informs the definition of health within the original as well as subsequent National Aboriginal Health Strategy documents.



2.2.5 Spirit, soul, place and time

Christianity, in a range of forms, has been widely adopted by Indigenous Australian communities. However, while recognising that accommodations, adaptations and diverse syncretisms are part of the *lived reality* of contemporary groups, Charlesworth (1998) suggests there is value, nevertheless, in recognising the distinctive frameworks of Christianity and Indigenous Australian religious practices respectively. He relies here on Stanner's earlier work (in the same volume), outlining a set of propositions that underlie the diversity of forms and specific beliefs of Aboriginal religious practices. Those with particular relevance to this review concern the nature of spirit and the purpose of being (1998:2):

'The human person, compound of body and several spiritual principles or elements, had value in himself and for others, and there were spirits who cared;

The material part of life, and of man himself, was under spiritual authority, and the souls of the dead shared in maintaining the authority and the providence over them;

The underlying philosophy of the religion was one of assent to the received terms of life ...'

The 'architectonic' idea (Stanner 1998:1) or organising principle is that all living people are linked by 'inherent and imperishable bonds' with ancestral beings. Thus at death and burial the intention is twofold — 'to enable the ghost of a dying or dead (person) to be quit of earthly ties and, to send the immortal soul to the place ... where his bones could lie at peace'. For some groups, the soul could later re-inhabit the human realm (Stanner 1998:13). The notion of immortality is fundamental to Indigenous Australian religious thought while various notions of re-birth or reincarnation also had and continue to have wide currency.

Ideas concerning the 'soul' are varied and include both those that correspond with the conventional (Christian) understanding of a unitary soul for each person through to notions of complex multi-component 'souls' (Strehlow 1964, 1971:598, Elkin 1937:288, Meggit 1962:317, Morphy 1984a:40) that incorporate different aspects of the self. Although death and the breakdown of the body ensues when the soul/s depart the body permanently, a soul or component of the spirit may also leave the body at other times without causing death. Strehlow, for example, (1964: 731) describes the Arrernte view that the experience of a person 'dreaming' is understood as that person's spirit travelling away from the body

into the realm from which it originated. Contemporary people of the area take care that a sleeping person is woken without haste or sudden fright so that the person's spirit will have proper time to return to the body⁸. In some areas people believe that dreams may include premonitions of death (Peile 1997:27).

Souls and/or spirits of the deceased are regarded by some as potentially dangerous (Rose 1992:72), as are the places where they may congregate, particularly modern day cemeteries (Hemming 2000). That said, however, the spirits of the dead in some senses have merged with the ancestral spirits and so inhabit the landscape. They represent a link to the land and to the human realm. Rose (1992:72) reports that Yarralin people 'stress the importance of living near the dead relatives' (in the sense of 'country' rather than 'cemetery').

Early commentators noted both a reticence in discussing the issue as well as a level of 'inconsistency' of accounts of what precisely becomes of the 'spirit' or soul (cf Elkin 1937) after death. Rose (1992:58), speaking of the Yarralin community in the 1980s, described that community as holding diverse ideas concerning the nature and fate of the 'soul'. She concluded that her search for a coherent set of beliefs was a consequence of her anthropological training and was itself a barrier to understanding the views being put to her — Yarralin people were not bothered by such inconsistencies.

A similar point is made by Dundiwuy Wanambi to Howard Morphy (1984a:41):

'Which way will the spirit go — to heaven or back to earth? When there had not been any missionaries we stuck to one story. The spirits meet up together in places like Buralku, Bremer Island or Rocky Point, if they are Dhuwa. And for the Yirritja moiety they meet up at Bulambula. Today we think in two ways — which way the spirit is really going. It is going back to the real homeland, or must it go to heaven, or perhaps to Buralku (the Dhuwa land of the dead). There are many possibilities to consider and we have no real proof until we die and then we will see what further words we have to say about the matter! It's very hard.'

⁸ Information given to JD by Ms Eileen Bird, Sandover River region Central Australia c 1990s



Similarly there are likely to be irresolvable ambiguities in response to death understood as either a doorway to eternal life (for Christians) — including potentially being reunited with previously deceased kin — or as an inevitable, but nevertheless, unnatural event (Eliade 1973:165) which, despite belief in spiritual immortality, saw the extinction of the individual person. Strehlow maintains that, if such views provided little comfort in the face of death, neither did they promote fear and he maintains that generally Arrernte people met death with stoicism (1971:602). In a footnote however he speculated that Arrernte found the Christian promise of a heavenly reunion of kin a powerful attraction to the religion.

The practice of conducting an ‘inquest’ or determination of who/what caused a particular death was widespread (Elkin 1974, Berndt 1981) and continues to have currency in many areas (Langton 1990). Unexpected deaths, particularly of young people, continue to arouse fear in communities and to be linked with accusations of blame (Weeramanthri 1995: 240).

In various areas contemporary Indigenous Australian Christians are formally articulating an explicitly ‘Aboriginal’ Christianity which can place the continuities of these foundational ideas of land, immortality and spirit within the matrix of Christianity. Such a theology they argue affirms their Aboriginality, since it takes ‘the land as a central spiritual reality’ as the starting point for all Aboriginal participants (Rainbow Spirit Elders 1997:vii). Such movements acknowledge the colonial and oppressive dimension of church and missionary activities as a strand of the colonial experience and remove Christianity as a spiritual path from the matrix of colonialism more generally (Rainbow Spirit Elders, and see Passi 1987).

‘The Dreaming’, or some variation of this term, is a widely reported concept referring to the period of creation when the ancestral figures formed the landscapes in which humans now live (Stanner 1979:23ff). Rose (1988, 1998) speculates that a different conceptualisation of time underpins the notion of The Dreaming, contrasting the non-linear ‘everywhen’ time of The Dreaming with that of the ‘ordinary’ time of everyday life. The Dreaming remains a central concept and its on-going re-interpretation recurs at many levels (cf the performances associated with the Sydney Olympics). Describing the emergence of Christian spirituality among a Yolngu group, Bos (1988) argues that these new religious ideas have been interpreted through the concept of The Dreaming in a way which has both enabled and facilitated social change,

‘ ... by maintaining an agreed body of symbols that are themselves sufficiently open-ended to be subject to re-interpretation.’ (1988:435)

2.2.6 Sensitivity of topic

The discussion of death and dying is a sensitive topic. It is approached — if at all — in very oblique terms by most Indigenous Australians. Many authors comment on the reluctance of people to engage in discussion around the subject of death — whether in relation to details of protocol, or of subjective meaning or particulars of specific deaths (Meggitt 1962:317, Reid 1983).

Nevertheless, we disagree with the conclusion of the initial literature review conducted for this project that the apparent sensitivity surrounding discussion of the topic is related to it being generally considered ‘sacred’ business.

‘... it seems logical to conclude that whilst there may be factors which make Indigenous Australian beliefs around death and dying unique, this project is not likely to identify these factors because they are ‘sacred business’. ... we conclude (therefore) that it would be useful to research indigenous palliative care initiatives recently developed in Canada and North America (unpublished).’

In contrast to this conclusion, there is strong evidence of productive engagement on this subject despite difficulties and sensitivities (cf Collis-McAnespie et al 1997, Freid 2000a & b, Weeramanthri 1995, 1996, Wake 1999). ‘Sacred’ is a relative rather than an absolute category and many dimensions of specific contexts determine the degree to which information is/is not provided (and see earlier). What is required, then, is a greater comprehension of, and sensitivity to, the more subtle differences between notions of ‘sacred’ as opposed to ‘secret’ and ‘private’, as well as more awareness of whether the associated emotional sensibility is that of respect, authority, shame, embarrassment, fear or something else.

There are a number of ‘kinds’ of silence concerning death and dying in the literature.

There is an ‘authoritative’ silence. We refer here to the choice by Indigenous Australians, at different times and places, now as well as in historic times, to restrict, limit, or in other ways prohibit the releasing of certain kinds of information into the public domain or out of the hands of those with authority to know it. This may include knowledge that is simply private business, or sensitive, or distressing as well as secret and/or sacred knowledge. Any or all of these kinds of knowledge might be withheld.



An authoritative silence may also refer to the reticence of Indigenous Australians to engage in discussion of what they perceive to be both socially and spiritually dangerous — for example, death and associated subjects. The widespread taboo on the use of names of the dead — especially the recently deceased — along with other purificatory actions such as ritual washing (Hart 1930, Berndt and Berndt 1964:389, Peile 1997:29, Strehlow 1971, Meggit 1962:323) can be interpreted as a recognition that a too-close association between the living and the recently dead is risky business unless specific precautions are taken (Berndt and Berndt 1968:410). Discussions around death, either in the ‘abstract’ or concerning a particular person are likely to be seen equally as risk-laden or socially dangerous activities — ‘unlucky’ in some sense⁹.

There is as well an ‘exclusionary’ silence where lack of engagement on a specific subject is more likely to indicate power differentials and marginalisation. This is the case of the lack of interest in the colonial experience of Aboriginal people compared to the on-going fascination with more ‘exotic’, and less disturbing, aspects of their lives and histories. Such a silence may also be apparent in contemporary service settings where Indigenous Australians often experience indifference to their responses and views on how matters might best proceed.

The topic of death and dying is sensitive and thus will require respect, thought and care if dialogue and discussion is to occur.

2.2.7 Disposal practices and associated rituals

Contemporary burials include contemporary choices — for example, interment in graves in the ground or cremation. In most instances too, burials are conducted using some form of Christian practice with graves being in conventional cemetery plots. There are some remoter localities where burial on one’s own country, outside of a designated cemetery, occurs routinely. In recent times too there is increasing interest among non-remote living people in burying people on or nearer their traditional country. The on-going significance of place of burial is reflected in the regularity of disputes including some which have involved formal mediation or litigation (Avery 2002).

⁹ Ms Sanchia Shibasaki speculating on why Torres Strait Islanders avoid such discussions. Pers comm 2003

Many Indigenous Australian communities have historically regarded cemeteries as important places of family history and connection. Rosie Borey — a Stradbroke Islander — recalls going on an all-day outings to the Myora Aboriginal Cemetery with her family during which time they visited, cleaned and decorated the graves. She noted the continuing tradition of grave decoration explaining how all the ‘shells on the graves were put there by all the Grannies’ (Borey 1984:15). Decades later, Bernice Borey (Borey 1984) mapped and documented all the Aboriginal graves in the Stradbroke cemetery.

The cemeteries of the Torres Strait are places rich in history and sentiment, in particular at the time of a Tombstone Opening with its associated spiritual, social and ritual activities (cf Jose 1998 and the photos of the Tombstone Opening day).

Contemporary Ngarrindjeri people regard burial sites (including historic and/or ancient burial sites) as places of considerable danger. Nowadays, children are not allowed to attend funerals or visit grave sites. Careful behaviour is required around cemeteries since the spirits of the dead continue to occupy the area and they may attempt to follow the living (Hemmings 2000:62). At the same time however, despite their (manageable) dangers, such places:

‘ ... provide contemporary Ngarrindjeri people with a physical and spiritual connection with their ancestors and with their ‘country’.’(Hemming 2000:63)

The Yolngu of Arnhem land now inter in graves in permanent cemeteries. The hollow log is still used though now rarely contain the deceased’s remains. The availability of local morgue facilities has lead to extended negotiations and rituals delaying final burial. Use of the morgue has entailed devising specific ceremonies to cover the transport of the body back to the community – such ceremonies ‘are based on analogous events in other contexts’ (Morphy 1984a:45).

There is considerable variation in regard to views of burial grounds, however, and some communities prefer to completely avoid gravesites and cemeteries following the actual burial ceremonies. Speaking of the Walbiri of Central Australia, Meggit (1962:327) notes that final interment of body is in an unmarked location known by few and not re-visited after final rituals are complete.



Changes are on-going. In Maningrida, for example, where hollow log coffins and bush burial were the norm, contemporary residents are now burying in graves in close vicinity to family residences within the community. Newer rituals include the use of a concrete grave cover with pre-set holes for flowers¹⁰. Similarly a recent funeral on Melville Island for a high profile Tiwi artist included a large photograph of the deceased on display¹¹.

Historically, an enormously diverse range of mortuary and burial practices have been practiced in Australia (Horton 1994:166, Berndt and Berndt 1964:Ch XIIIff) including disposal undertaken as a single event (burial, cremation, deposition in caves and trees) or disposal in a sequence of events or stages carried out over time varying in length from months through to years. The sequence involved firstly the primary burial or exposure; secondly the preparation of remains for keeping with family for periods up to years; and then the final interment of remains (cf Morphy 1984a:42). Historically, cremation was a major form of primary disposal (for example, a single event) in much of coastal eastern Australia from Cape York through to Tasmania (Hiatt 1969).

There are traditional cemeteries created at least 12,000 years ago along the middle parts of the Murray Valley, Kow Swamp and Coobool Creek. Burials were carried out along the Murray River as far as its mouth up until contact (Horton, 1994:185).

10 Dr Betty Meehan pers comm 2003

11 James Bennett pers comm 2003

3 Working with social and cultural diversity in palliative care

It is well established that palliative care services need the capacity to respond appropriately as well as effectively to a culturally diverse clientele. Nevertheless, the literature relating to the many issues that arise in cross-cultural care settings remains underdeveloped both in Australia and elsewhere (Fried 2000:20, Campbell et al 2000). A series of key Australian commissioned reports (see Section 1) provide information in relation to palliative care needs for particular regional Indigenous Australian populations. Specific ‘cultural’ issues (for example, importance of homeplace, communication, role of elders, etc) are identified within these reports. However, the broader principles and underpinning assumptions of strategies aimed at building culturally responsive services — as opposed to services appropriate for Indigenous Australian clients — are largely bypassed in these reports. Before considering the issues of working with diversity, however, there is a more general point to make.

3.1 System level responses

From the outset — drawing on our combined experience — we suggest that there are *specific system level components that need to be in place* to capitalise on any benefits that may flow from more effective client/practitioner engagement. Without supportive systems, efforts in relation to improved engagement with individual clients and their families will be dissipated. Key system features that would promote a service that is responsive to diversity, specifically in relation to Indigenous Australians include:

- consulting with clients and their organisations to *develop policies* outlining the service’s position in relation to working with social and cultural diversity
- *employing Indigenous Australians* in decision-making positions as well as operational spheres
- *negotiating protocols* with local Indigenous Australian groups concerning issues jointly identified (as problematic)
- incorporating *system-level review cycles* so that protocols and system components are updated, refined, et cetera
- identifying pathways for *induction of new staff*.



Analysis and commentary on palliative care at the cultural interface in Australian settings has been undertaken primarily by Campbell, Moore and Small (2000), McNamara et al (1997), Waddell and McNamara (1997), Fried (1999, 2000a & b, 2003) and Prior (1997, 1999, 2001), with the latter two having a focus solely on palliative care for Aboriginal populations. To date this growing 'Aboriginalist' literature in palliative care has not intersected productively with literatures examining culture and/or cultural difference as a social process. This gap is not confined to palliative care. One consequence is somewhat separate literatures of multicultural services on the one hand and services for Indigenous Australians on the other. For reasons noted earlier, it is likely that Indigenous Australians themselves may wish to structure their relationship to the broader society in ways that clearly distinguish them from immigrant groups such as Italians, Vietnamese, et cetera, and therefore will reject — socially as well as politically — their own inclusion under the label 'multicultural' (Prior 1999:103). Nevertheless, if the concept of 'culture' itself *has* any analytical value it needs to draw on, as well as account for, not only Indigenous cultures but those of immigrant peoples including — and this needs some emphasis — the culture of Anglo-Australians. Conversely, the failure of the Aboriginalist literature in palliative care (and health services more generally) to problematise the term 'culture' (cf Rowse 1996) creates its own obstacle to a clear focus on the path to improvements.

The concept of 'cultural safety' (see Section 1) extends the analytic reach of the notion of 'culture' through directing attention away from a narrow conceptualisation of 'culture' and turning the focus firmly in the direction of the health professional and the service setting (Ramsden 2002). Considerations of cultural safety involve firstly understanding — as a health professional — how/if one's own social and cultural patterns (particularly attitudes and values) determine one's own practice and, secondly, whether the resultant practice 'diminishes, demeans or disempowers the cultural identity of an individual' (Olivier 1999:54).

However, operationalising the framework of cultural safety will require careful, systematic work: the practical application of this approach in Australian settings remains undocumented. Given that one of the distinguishing characteristics of culturally-based assumptions is that they are not necessarily held consciously nor commonly articulated in everyday life (Section 1), it may not be straightforward for a practitioner to specify, with an adequate level of completeness, the relevant assumptions, values and attitudes underlying their practice and/or their own social responses to clients. This is complex territory.

3.2 More than 'culture'

There is a body of health literature critiquing the range of approaches centring on culture including 'multicultural' frameworks as well as cultural profiling. Such 'culturalist' approaches (Culley 1996:566) are seen as being not only inadequate analytically but also highly problematic when uncritically operationalised within professional development and service delivery systems. Culturalist approaches propose cultural difference as the primary variable accounting for differences in health needs and service use¹². Culley (1996) and Gunaratnam's (1997) cogent critiques of this position have most salience for palliative care. Additional key references cited by them, but not read by the reviewers include Pearson (1986) and Rattansi (1992).

Commentators critical of a culturalist approach do not deny either the existence of cultural differences or the importance of considering culture in establishing effective and appropriate palliative care services. This needs some emphasis. As Culley (1996:566) notes:

'The fact of cultural difference is not contested. What the culturalist framework tends to ignore however, is the power relations which exist between 'cultural groups'.'

The concept of 'cultural safety', if understood in its (distorted) 'weaker sense' (as in the transcultural nursing approach, Ramsden 2002) also lies within a culturalist framework insofar as it proposes 'culture' as the critical domain for analysis of the interaction. Gunaratnam (1997:179) argues that:

'Because (cultural profiles) are constructed around the benign description of cultural and religious practices, they overwhelmingly neglect to address (those) ambivalences and power relations which criss-cross and continually destabilise cultural practices.'

¹² Recall the earlier observation that 'culture' is almost never invoked as a variable to describe health differentials in the majority Anglo-Australian population



Using data from palliative care service providers and examples of institutional responses (for example, to collective public wailing) she points out that fundamental — and real — tensions existing between organisational requirements and the equally real needs of particular client groups are essentially ignored through an alternative focus on a set of predetermined ‘cultural attributes’. Thus the ‘multi-cultural narrative’ ignores real conflicts of interest between users and health professionals and ‘obfuscates the nature of organisational and political barriers to meeting the needs ... of minority people’.

While accepting that some level of knowledge of cultural processes is essential for staff, Gunaratnam (1997:184) concludes that unless tools like these descriptive ‘factfiles’ are located within a ‘dynamic and politicised conceptual framework’, they will remain simply a ‘management’ tool rather than a ‘radical empowerment process’.

Moving the focus of working with diversity away from a dominant concern with ‘culture’ — particularly the culture of the ‘other’ (client) — still leaves open the question of how a service might operationalise such an analysis, both in terms of professional practice education as well as service settings. The waters here are basically uncharted. The Indigenous Australian palliative care literature — while growing — lacks specificity around the management of diversity (Fried 2000:41). A certain circularity along the following lines is often apparent: the problem is that clients are culturally different: the answer is culturally appropriate practices/services/resources. But, as noted above, the tendency is to skip over the hard questions — for example, what precisely does ‘culture’ mean? Instead there is a pre-occupation with specifying cultural particularities. A partial remedy here lies in designing a ‘cross-cultural’ education that includes a critical examination of the concept of ‘culture’, especially in relation to cross-cutting notions such as race, identity, gender, ethnicity, nationality, class, socio-economic status and so on.

3.2.1 Identifying need

In an interesting account of Australian palliative care practitioners’ self-reporting of cross-cultural competence, McNamara et al (1997), identified nine domains of routine service within which difficulties arose. Practitioners rated their own competence in each domain in relation to three different (non-Indigenous Australian) cultural groups. The authors argue that professional education is the avenue to improving cultural competence and suggest that these nine domains provide ‘the basis of suggested guidelines for proposed education programs’ (1997:359).

The domains (not in any priority order) are:

- bereavement counselling
- spiritual care
- discussing diagnosis/prognosis with the patient
- discussing diagnosis/prognosis with the family
- traditional therapies
- other communication
- ability to assess the patient
- discussing their role
- language.

For clients/families (Vietnamese) who did not have a language in common with the carers, all domains were rated as more difficult. Practitioners also reported differences in regard to the level of difficulty between domains. For example, within all three groups 'bereavement counselling' was identified as a difficult area; 'spiritual care' was a difficult issue within the Anglo-Australian group. The authors acknowledge that this view of 'competence' is rather one-sided since no attempt was made to ascertain whether these domains coincided with those perceived as most difficult by clients and families, nor did the study assess how clients rated practitioners' competence. However, it usefully illustrates how a service systems investigation might be structured, so that it acknowledges 'cultural difference' and addresses the client group's needs, without necessarily concentrating on the client group's culture. The domains identified may not encapsulate all considerations for an appropriate and effective service for Indigenous Australians, but they provide a basis for further development, including identifying areas/processes/protocols that are likely to generate conflict.

There is considerable overlap between this and the approach of Campbell et al (2000) who provide a set of 'ethical and cultural issues' including:

- communication
- language
- specific ethical concerns
- disclosure
- autonomous decision-making
- consent in relation to medications, food and clothing, presence with and access to patient, and care of the body.



The likely areas of conflict and the complexities within each of these domains are usefully described. While the particularities of various ‘cultural’ groups’ needs in relation to any or all of these domains may be different, (for example, religious protocols/rituals in relation to the body and views on full disclosure of patient condition), these are the topics within palliative care in which a practitioner may expect to encounter divergent values and practices. This kind of system-level specification of the elements of a service that is responsive to difference holds greater potential for adjustment, review and refinement than the process of enumerating perceived points of ‘cultural’ difference. Conversely, this approach is also less likely to degenerate into a subjective, parochial and essentialising approach to diverse client groups as well as the diversity of individuals within those groups.

3.2.2 Professional education and resources

McNamara et al (1997) also conceptualise ‘resources’ in a way that supports a strategic approach to developing a responsive system.

Resource	Specified areas
People	Health care professionals of the same cultural background as the patient Volunteers of the same cultural background as the patient Ethnic liaison professionals Family members
Education	Lectures by professionals and ethnic community representatives Interactive workshops with professionals and ethnic community representatives Short courses on culturally appropriate palliative care Written resources including handbooks, guidelines and library resources Visual aids including videos and posters
Language aids	Dictionary of common medical and lay terms in different languages with phonetic pronunciation Communication Boards to facilitate language translation Brochures for patients in different languages describing palliative care services
Interpreter service	Hospital interpreter service Telephone interpreter service

Clearly, palliative care providers dealing with Indigenous Australian communities would need to make additions and qualifications to this¹³.

In relation to professional education Fried (2000a:22) argues that the extent to which ‘empathy’ and good interpersonal skills can provide a bridge to cross-cultural practice is uncertain. She suggests (2000a:91) that at least four elements are needed to develop a ‘culturally inclusive and responsive service’:

- sensitivity
- specific cultural knowledge
- reflective practice in relation to cultural competence
- appreciation of historical and political concomitants of cross-cultural practice.

Of these, both reflective practice and the incorporation of contextualising social and political history offer key additional domains.

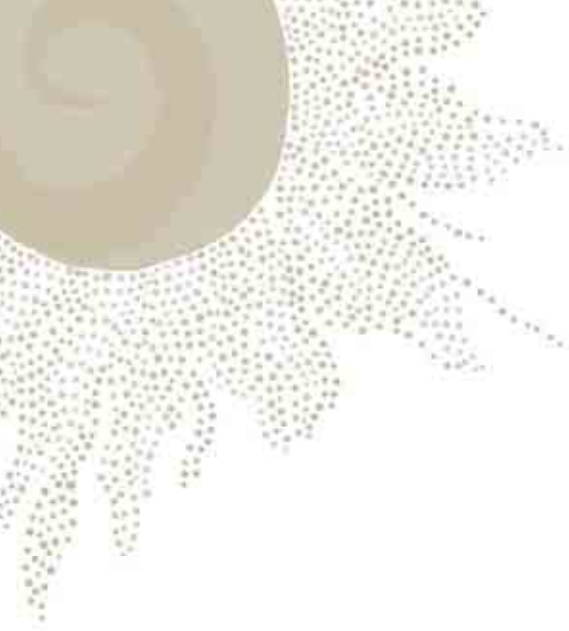
Davidson (2000) emphasises the importance of recognising and understanding the ‘affective’ or emotional terrain of an inter-cultural encounter, particularly since Anglo-Australians tend to downplay or ‘suspend’ that dimension of relationships especially when in a work setting. This is a point of significant cultural difference and one with ramifications for effective communication.

In concluding, we note that the review brief asked for a summary of the ‘basic principles of intercultural communication’. For reasons outlined above, we have re-framed the focus of the review such that it considers the basic principles of *working with diversity*. In essence this signals that just as ‘communication’ is only one dimension of an effective palliative care service, so ‘inter-cultural communication’ is but one dimension of a palliative care service that effectively engages with clients of diverse social and cultural backgrounds.

Working effectively in palliative care to address social and cultural diversity requires practitioners to move away from a pre-occupation with ‘culture’ as an attribute of the client. Instead there is a need for a critical assessment of system level approaches and a reflective practice by the individual practitioner that moves practice towards that which affirms the needs of Indigenous Australian clients.

¹³ For instance, interpreters are scarce for most Aboriginal languages and not available for many; telephone interpreting does not extend to Aboriginal languages; written Aboriginal language documents are not the most effective way to provide accessible information





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Appendix 1

Methodology

This Discussion Paper sets out to answer several different and broadly posed questions (see brief) on a subject — death and dying — which can be studied from a multitude of disciplinary and theoretical positions. Moreover, we have the task of surveying literatures concerned with a knowledge of the subject of death and dying as well as literatures providing insights into the provision of (culturally responsive) services. While we have approached these task systematically, we have not undertaken what is conventionally termed a ‘systematic’ review (cf the Cochrane-type). Both the level of generality of the questions posed as well as the kinds of literature being reviewed preclude such a tightly circumscribed approach. While it might be technically possible to carry out such a review — for example, by reframing the questions more narrowly — the outcome would be unlikely to either justify the effort, or sufficiently support the palliative care project. The complexity of the theoretical, social and historical and other questions encapsulated in considerations of death, dying and palliation (and indeed in most questions of social substance) demands a more nuanced and less restrictive method.

Speaking more generally, it is an ongoing concern that the narrowness of the ‘evidence-based’ conceptual apparatus now so heavily relied on by many health and medical professionals can rule out much social scholarship from their consideration. For example, Kellehear (2002:85:176) suggests that an overly narrow disciplinary base of much past research into grief and loss has obscured our understanding of both the process itself as well as optimal management and/or support responses.

We have therefore undertaken our review of the literature via several pathways, as well as incorporating suggestions made in the brief.



Firstly we have attempted to broadly survey the field through the following specific survey strategies:

- Standard database searches

We engaged a librarian to undertake searches of databases — particularly APAIS, AMI and theses databases — as well as the Internet for material relevant to Indigenous Australians around the key words: death/dying/grief/loss/bereavement and intercultural communication/cross-cultural practice/reflective practice.

- Key special collections searches:

A week was spent at the Australian Institute for Aboriginal and Torres Strait Islander Studies (AIATSIS); 'Health Infonet' — the electronic Health collection auspiced by Edith Cowan University in Western Australia; Aboriginal health published articles collection, Menzies School of Health, Darwin.

- Ethnographic/anthropological literature searches

We have attempted to achieve a sense of both geographic and historical perspective in our search of this literature. That entailed seeking out particular authors who have written on specific geographic areas as well as reviewing the works of 'old' authors such as Elkin, Strehlow, Meggit and some of their less well known (outside anthropology) 'descendents' (for example, Myers, Merlan, Morphy, McDonald).

- Sociological/psychological literature including suggested key authors and reports.

- Health Services literature including the (recent) work directly arising from palliative care services reports and related projects (for example, Sullivan et al 2003).

- Networking with service providers and others to locate specific literature/resources.

From this survey of the field we provide a description of the various approaches to the subject and the kinds of literatures they have generated. Note that this does not entail any process of comparative coding to construct an index of the relative merits of all the work surveyed. As noted above, this could not be done for this kind of review. However, clearly all literature is not of equivalent merit and we have identified key resources around several specific topics.

The surveyed literature covers an enormous range of empirical data, as well as traversing several disciplinary territories and theoretical orientations. Therefore, we have adopted a 'thematic' approach. We present a critical review of key issues with bearing on the subjects.

We present the key issues firstly in terms of 'features' of the literature, and secondly in terms of important 'themes'. We have also identified a series of 'critical concepts' which have bearing on both the subject of death/dying and on intercultural communication. The concepts are important in several ways: some assist in understanding the literature (for example, shifting paradigms), some relate to resource preparation (for example, inter-disciplinary borrowing) and some might properly be objects of study by practitioners and be the subject of specific resources (for example, culture racism, cultural safety). Some concepts have bearing on all of these aspects of the project.





Appendix 2

Patterns of death of Indigenous Australians in contemporary Australia – the statistics

Introduction

The data presented here is drawn from the most recent analyses (2001) provided jointly by the Australian Bureau of Statistics (ABS) and the Australian Institute of Health and Welfare. The publication (*The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples*, Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2003, Commonwealth of Australia) contains a wealth of data presented in an accessible format with explanations and guidance in the interpretation of the data. The factors which influence the quality of the available data include:

- difficulties in accurately counting (at Census time) the Indigenous Australian population
- jurisdictional variability in completeness of Indigenous Australian identifications
- invisibility of Indigenous Australian populations within standard samples for national household surveys.

Data presented

The first category of data describes the Aboriginal population, including distribution by:

- State and Territory (Tables 1 and 2)
- remoteness (Figure 2)
- age/sex (Figure 1).



The second category of data describes key mortality data including:

- Aboriginal deaths as a proportion of total deaths by age groups (Table 3)
- rates of death by age (Table 4)
- selected causes of death (Table 5)
- non-disease related deaths covering accidents, suicides, assault (Table 6).

Similar material for Torres Strait Islanders (where available) is contained in Tables 7, 8, 9 and 10.

In terms of information relevant to the provision of palliative care and the kinds of information presented in the earlier sections of the report, the statistics show that:

- Indigenous Australian populations are comparatively young, with half of these populations being younger than 20.5 years in June 2001
- compared with non-Indigenous Australians, there are relatively fewer Indigenous Australians (< 10 per cent) in the 55 to 75 plus age groups
- around half the total Aboriginal population lives in either New South Wales or Queensland; these two states in combination are home to over 200,000 Aboriginal people
- the Northern Territory has the highest proportion of Aboriginal people (28 per cent), but a relatively low absolute number of people (around 50,000)
- the majority of the Aboriginal population — around 70 per cent — live in either cities or inner/outer regional centres with the remaining 30 per cent in remote to very remote localities
- Torres Strait Islanders number around 43,500 in total, including around 17,000 who identify as being both Aboriginal and Torres Strait Islanders
- around 58 per cent of Torres Strait Islanders live in Queensland, and about 1 in 4 of these live in the Torres Strait Islands
- outside of Queensland (and the Torres Strait Islands) the greatest number of Torres Strait Islanders live in New South Wales (17 per cent) and the lowest in the ACT (< 1 per cent)
- the age/sex profile of the Torres Strait Islander population is almost identical to that of Aboriginal Australians.

Table 1

POPULATION MEASURES — 30 JUNE 2001						
	Census place of enumeration 7 August 2001		Census usual residence 7 August 2001		Experimental ERP(a) 30 June 2001	
	Indigenous no.	Total no.	Indigenous no.	Total no.	Indigenous no.	Total no.
New South Wales	119,865	6,311,168	120,047	6,326,579	134,888	6,575,217
Victoria	25,078	4,612,097	25,059	4,660,991	27,846	4,804,726
Queensland	112,772	3,585,639	112,575	3,522,044	125,910	3,628,946
South Australia	23,425	1,458,912	23,377	1,470,057	25,544	1,511,728
Western Australia	58,496	1,832,008	58,467	1,828,294	65,931	1,901,159
Tasmania	15,773	454,841	15,856	460,672	17,384	471,795
Northern Territory	50,785	202,729	50,845	188,075	56,875	197,768
Australian Capital Territory	3,576	309,184	3,548	309,998	3,909	319,317
Australia(b)	410,003	18,769,249	410,003	18,769,249	458,520	19,413,240

(a) Final rebased experimental Indigenous estimated resident population as at 30 June 2001.
 (b) Includes Other Territories.

Source: Population Distribution, Aboriginal and Torres Strait Islander Australians, 2001, ABS cat. no. 4705.0, ABS data available on request, 2001 Census of Population and Housing.

Figure 1

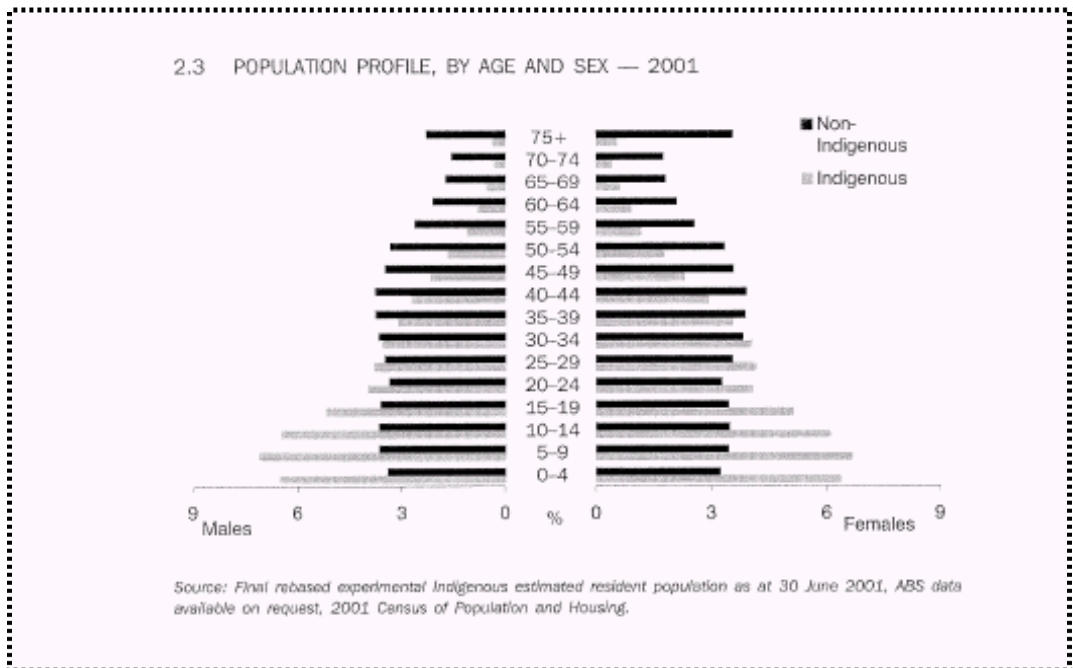


Table 2

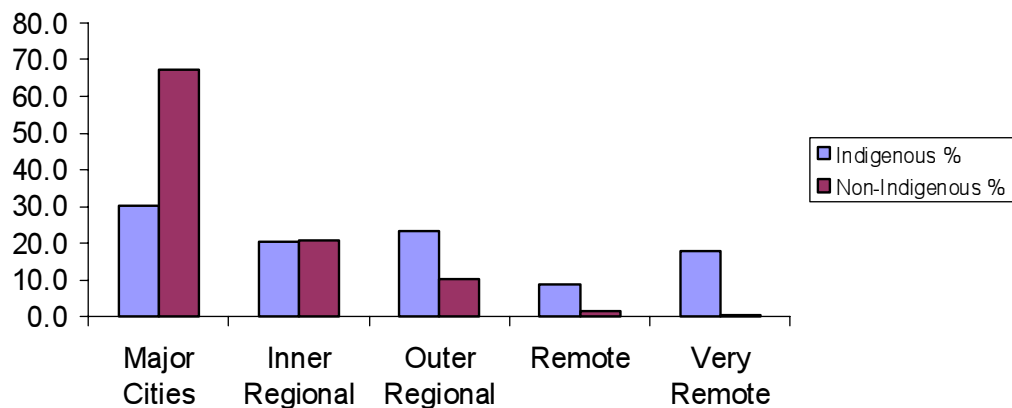
	Indigenous population	Proportion of the total Australian Indigenous	Proportion of the total state or territory population
	no.	%	%
New South Wales	134,888	29.4	2.1
Victoria	27,846	6.1	0.6
Queensland	125,910	27.5	3.5
South Australia	25,544	5.6	1.7
Western Australia	65,931	14.4	3.5
Tasmania	17,384	3.8	3.7
Northern Territory	56,875	12.4	28.8
Australian Capital	3,909	0.9	1.2
Australia(b)	458,520	100.0	2.4

(a) Final rebased experimental Indigenous estimated resident population as at 30 June 2001.
(b) Includes Other Territories.

Source: ABS data available on request, Demography, 2003.

Figure 2

ESTIMATED RESIDENT POPULATION BY REMOTENESS AREAS(a) - 2001



(a) Final rebased experimental Indigenous estimated resident population as at 30 June 2001.

Source: ABS data available on request, 2001 Census of Population and Housing

Mortality statistics

The ABS source document has extensive material on mortality; an outline sketch of that material is provided here to quantitatively contextualise what is being experienced and described by community members themselves as well as care providers. The picture is bleak.

- For both men and women, life expectancy for Aboriginal people is 20 years less than for all Australians.
- Aboriginal Australians in every age group (male as well as female) are over-represented in mortality statistics relative to other Australians.
- Infant mortality is 2.5 times higher than that of other Australians.
- Leading causes of death (in order) are diseases of circulatory system, accidents, suicides and assaults and cancers.
- The highest standardised mortality ratios for males as well as females were 'endocrine, nutritional and metabolic disorders' described by the ABS as predominantly due to Diabetes Mellitus (Type 2).
- Diseases of the circulatory system accounted for the highest proportion of excess deaths.
- Violent deaths – accidents, suicides and assaults – are the second highest cause of excess death, particularly among young men between 15 and 34 years of age.

Among Torres Strait Islanders, the causes of death are similar to that of Aboriginal people however there is some difference in the age profile of deaths with more deaths among people in the youngest ages (1 to 14 years) and then in the older ages (55 years and over). Comparative data is not available for all the items above.



Table 3

INDIGENOUS DEATHS(a) — 1999–2001				
Age group (years)	Indigenous deaths as a proportion of total deaths		Indigenous persons as a proportion of total population	
	%		%	
Less than 1	19.1		7.4	
1–4	16.6		7.1	
5–14	14.5		6.4	
15–24	12.6		4.9	
25–34	13.5		3.9	
35–44	13.6		2.8	
45–54	9.0		1.9	
55–64	5.5		1.4	
65–74	2.6		1.0	
75 and over	0.8		0.5	

(a) Data are for Queensland, South Australia, Western Australia and Northern Territory combined. Based on year of registration.

Source: ABS data available on request, Deaths Registration Database.

Table 4

AGE-SPECIFIC DEATH RATES(a) — 1999–2001								
Age group (years)	Males				Females			
	Indigenous rate(b)	Total rate(c)	Rate ratio(d)	Total Australian rate	Indigenous rate(b)	Total rate(c)	Rate ratio(d)	Total Australian rate
Less than 1(e)	16	6	2.6	6	12	5	2.5	5
1–4	74	36	2.0	30	67	24	2.8	24
5–14	37	17	2.2	16	30	12	2.4	11
15–24	252	99	2.5	89	100	35	2.8	34
25–34	448	134	3.3	126	201	52	3.9	47
35–44	873	174	5.0	161	467	89	4.7	89
45–54	1,562	318	4.9	310	975	199	4.9	196
55–64	3,107	838	3.7	832	2,147	481	4.5	484
65–74	6,085	2,418	2.5	2,426	4,182	1,342	3.1	1,348
75 and over	11,006	8,158	1.3	8,179	9,326	6,508	1.4	6,546

(a) Per 100,000 population.
 (b) Data are for Indigenous deaths for usual residents of Queensland, South Australia, Western Australia and Northern Territory.
 (c) Data are for total deaths of usual residents of Queensland, South Australia, Western Australia and Northern Territory combined, including Indigenous deaths. Based on year of registration.
 (d) Indigenous rate divided by the total rate.
 (e) Per 1,000 live births.

Source: ABS data available on request, Deaths Registration Database.

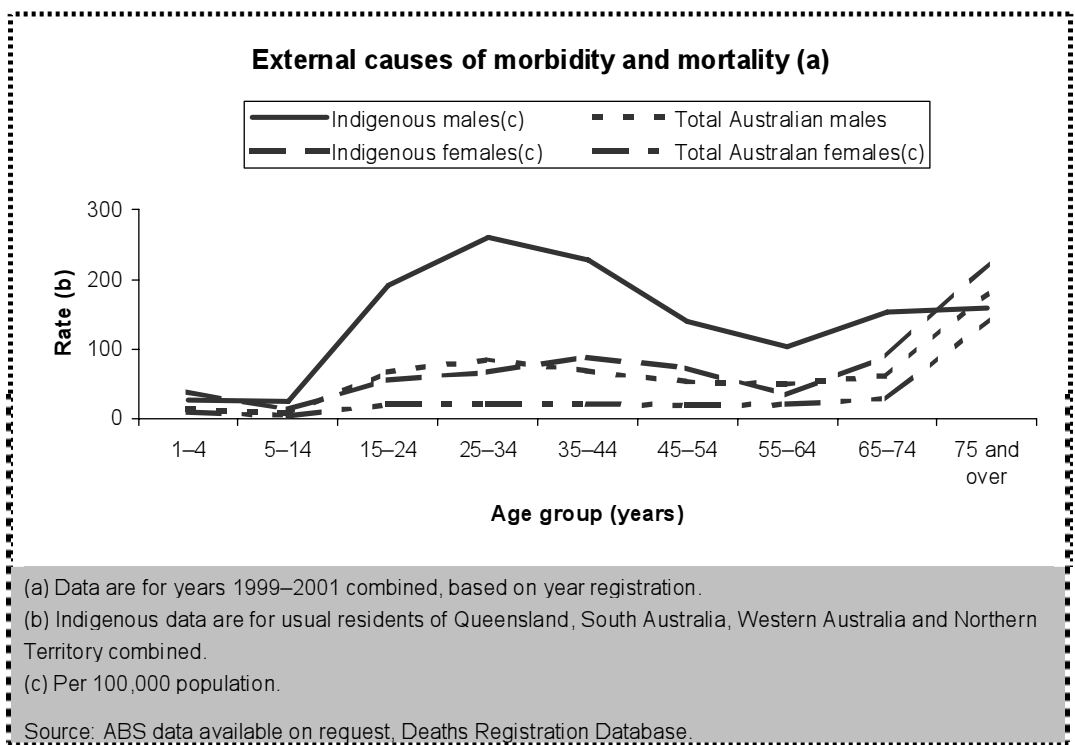
Table 5

	Males		Females	
	Deaths	SMR(b)	Deaths	SMR(b)
Diseases of the circulatory system	680	3.2	519	2.8
External causes of morbidity and mortality	512	2.9	203	3.2
Neoplasms	347	1.6	289	1.6
Diseases of the respiratory system	206	4.4	154	3.9
Endocrine, nutritional and metabolic diseases	181	7.9	236	11.7
Diseases of the digestive system	110	4.8	89	4.8
Mental and behavioural disorders	77	4.1	26	1.9
Certain infectious and parasitic diseases	68	5.2	48	5.3
Diseases of the nervous system	59	2.4	48	2.1
Diseases of the genitourinary system	56	6.2	94	8.7
Symptoms, signs and abnormal findings n.e.c.	74	6.1	40	5.0
All causes	2,518	3.1	1,867	3.0

(a) Data are for Indigenous deaths for usual residents of Queensland, South Australia, Western Australia and Northern Territory combined. Based on year of registration.
 (b) Standardised mortality rate = observed deaths divided by expected deaths, based on total Australian age, sex and cause-specific rates.

Source: ABS data available on request, Deaths Registration Database.

Table 6



*Providing culturally appropriate palliative care to
Aboriginal and Torres Strait Islander peoples*

Table 7

AGE DISTRIBUTION — 2001

Age group (years)	Units	Torres Strait area	Rest of Australia	All Australia			
		All Torres Strait Islanders	All Torres Strait Islanders	All Torres Strait Islanders	Aboriginal	Non- Indigenous	Total(a)
0-14	%	40	40	40	39	20	21
15-34	%	31	33	33	34	28	28
35-54	%	20	19	19	20	29	29
55 and over	%	9	8	8	7	22	22
Total	%	100	100	100	100	100	100
Population	no.	6000	37574	43574	366429	17591489	18769249

(a) Includes persons for whom Indigenous status was not stated.

Source: ABS data available on request, 2001 Census of Population and Housing.

Table 8

**EXPERIMENTAL INDIGENOUS ESTIMATED RESIDENT POPULATION(a) BY STATE WITH PROPORTION OF
ALL PERSONS OF TORRES STRAIT ISLANDER ORIGIN — 2001**

	Torres Strait Islander	Both Torres Strait Islander & Aboriginal	All Torres Strait Islanders	All Torres Strait Islanders	Aboriginal no.	Non- Indigenous no.	Total no.
	no.	no.	no.	%			
New South Wales	4770	3887	7679	17.7	126231	6440329	6575217
Victoria	1913	1147	2780	6.3	24786	4776880	4804726
Queensland	18525	10105	25440	58.7	97280	3503036	3628946
South Australia	837	575	1344	2.9	24132	1486184	1511728
Western Australia	962	1492	2200	5	63477	1835228	1901159
Tasmania	1375	986	2179	4.8	15023	454411	471795
Northern Territory	679	1239	1661	3.9	54957	140893	197768
Australian Capital Territory	164	121	277	0.6	3624	315408	319317
Total(b)	29239	19552	43574	100	409729	18954720	19413240

(a) Experimental Indigenous Estimated Resident Population, final rebased figures at 30 June 2001.

(b) Includes Other Territories.

Source: ABS data available on request, 2001 Census of Population and Housing.

Table 9

TORRES STRAIT ISLANDER DEATHS BY AGE GROUP						
Age group (years)	Torres Strait Islander(a)	Proportion of total Torres Strait Islander deaths		Total Indigenous	Proportion of total Indigenous deaths	
	no.		%	no.		%
MALES						
0–14	13		12.4	102		8.4
15–34	17		16.2	203		16.6
35–54	17		16.2	354		29.1
55 and over	58		55.2	559		45.9
Total	105		100	1218		100
FEMALES						
0–14	9		14.8	69		8.2
15–34	5		8.2	90		10.7
35–54	14		22.9	234		27.7
55 and over	33		54.1	452		53.5
Total	61		100	845		100
PERSONS						
0–14	22		13.2	171		8.3
15–34	22		13.2	293		14.2
35–54	31		18.6	588		28.5
55 and over	91		54.9	1011		49.0
Total	166		100	2063		100

(a) Includes 'Both Aboriginal and Torres Strait Islander'.

Source: ABS 2002, **Deaths, Australia, 2001**, cat. no. 3302.0, ABS, Canberra.
ABS data available on request, Deaths Registration Database.

Table 10

CAUSES OF DEATH — 2001						
	Torres Strait Islanders(a)	Proportion of total deaths		Total Indigenous	Proportion of total deaths	
	no.		%	no.		%
Malignant neoplasms	30		18.1	329		15.9
Endocrine, nutritional and metabolic diseases	14		8.4	173		8.3
Diseases of the circulatory system	48		28.9	595		28.8
Diseases of the respiratory system	15		9.0	194		9.4
Diseases of the digestive system	5		3.0	96		4.6
External causes of morbidity and mortality	24		14.5	343		16.6
Total(b)	166		100	2063		100

(a) Includes 'Both Aboriginal and Torres Strait Islander'.

(b) Includes all causes of death.

Source: ABS 2002, **Deaths, Australia, 2001**, cat. no. 3302.0, ABS, Canberra.
ABS data available on request, Deaths Registration Database.

