

Seven Principles for Indigenous Palliative Care Service Delivery: Research Findings from Australia

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ABSTRACT

In any society, the response to health and illness is shaped by cultural traits, values and rules and learned through participation in that society. In Australia, there are significant cultural differences in the way disease and death are dealt with and understood by the dominant Anglo-Australian society and by Aboriginal peoples. The implications of such cultural differences are particularly poignant during the dying trajectory. As palliative care has only recently begun to address the cultural needs of Indigenous Australians, there is scant literature available on the topic. In order to address this hiatus, the present article provides findings from a National Health and Medical Research Council two-year study on Indigenous palliative care conducted in the Northern Territory that documents a model for end-of-life care for Aboriginal peoples. The purpose of this article is to present the findings informing the seven principles (equity; autonomy/

empowerment; trust; humane, non-judgmental care; seamless care; emphasis on living; and cultural respect) that underpin the model. The articulation of the seven principles has been developed through extensive consultation with Aboriginal peoples and health professionals throughout the Northern Territory. As the principles have now been reviewed and affirmed by a diversity of national audiences, it is with confidence that the authors offer them as a practical starting point for ensuring that excellence in end-of-life care is provided for Australia's first peoples. In so doing, it is the authors' hope and expectation that the principles will provide insights for others working with Indigenous peoples around the world.

INTRODUCTION

In any society, the response to health and illness is shaped by cultural traits, values and rules that are learnt through participation in that society.¹ In Australia, there are significant cultural differences in the way disease and death are dealt with and understood by the dominant Anglo-Australian society and by Aboriginal peoples.² Indeed, as McMichael³ reports, there are 'profound cultural dissonances' between Aboriginal and non-Aboriginal beliefs in relation to health and health care. For example, there is no Indigenous word for cancer and the Western biomedical language that semantically constructs the notion of cancer is not widely understood by Aboriginal peoples. In addition, for many Indigenous peoples, the aetiology of cancer is embedded in beliefs about the spiritual world of curses and

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payback from perceived misdeeds.⁴ The only notions shared with the Western view are that cancer is a frightening disease and has serious life-threatening consequences.⁴ Thus, in view of the significantly different world views held by Indigenous and non-Indigenous Australians, cultural respect and sensitivity are of central importance in ensuring the effectiveness of any health care delivery to Aboriginal peoples diagnosed with, or treated for, cancer.

The implications of cultural difference are particularly poignant during the dying trajectory.^{5,6} However, palliative care has only recently begun to address the cultural needs of Indigenous Australians and so there is scant literature available on the topic. In order to address this hiatus, the present article provides findings from a National Health and Medical Research Council (NH&MRC) two-year study on Indigenous palliative care conducted in the Northern Territory that documented a model for end-of-life care for Aboriginal peoples. The purpose of this article is to present the findings informing the seven principles (equity; autonomy/empowerment; trust; humane, non-judgmental care; seamless care; emphasis on living; and cultural respect) that underpin the model. The articulation of the seven principles has been developed through extensive consultation with Aboriginal peoples and health professionals throughout the Northern Territory. The principles of care have been shared with, and resoundingly affirmed by, a diversity of consumer, practitioner and academic audiences around Australia and internationally. Communications from individuals and organizations in locations including Canada, the USA and the UK indicate that the principles resonate with best practice for Indigenous peoples in other countries. The aim of this article is to respond to the considerable and continuing requests to make the principles available through publication.

METHODOLOGY

The data for the model development were collected through open-ended, qualitative interviews with a cross-section of participants (consumers and health professionals) throughout the Northern Territory. The model developed from the data was assessed by a national review panel of experts in Indigenous health and at a meeting of the Northern Territory Aboriginal Reference group. The model and seven principles have been affirmed by a wide range of national audiences.^{8,9,10} The qualitative data collected to inform the model development is extensive and rich and hence is being published in a number of articles in order to do justice to the material. The findings under discussion in this article refer to the data that documents and elaborates on the principles that were reported as essential for effective end-of-life care of Aboriginal peoples.

Ethics Clearance

This project was conducted in compliance with the NH&MRC guidelines on ethical matters in Aboriginal and Torres Strait Islander Health Research,¹¹ and the Australian Institute of Aboriginal and Torres Strait Islander Studies' guidelines for ethical research in Indigenous Studies.¹² Permission and authorisation was obtained from a number of research ethics committees: The Human Research Ethics Committee of the Department of Health and Community Services (formerly Territory Health Services); Menzies School of Health Research, Darwin; The Central Australian Ethics Committee, Alice Springs; The Human Research Ethics Committee of Charles Darwin University (formerly Northern Territory University); and the Central Queensland University Ethics Committee. Approval was sought from relevant Community Councils (Chairs/Elders as appropriate) and from all individuals prior to participating in the project.

Research Focus

The research questions informing the data collection included:

1. What palliative care services are provided, and are they meeting the clients' needs?
2. How can the services be modified to deliver a culturally appropriate, innovative and exemplary model?
3. What strategies are needed to develop and apply the model developed?

In short, the research was concerned with: What is? What works? What is needed? The outcome is a 'Living Model',¹³ which is a generic model incorporating all important factors that can be applied to the unique circumstances of each health care service working with Indigenous people during the end-of-life trajectory.

Participant Group

The research team included an Aboriginal Health Worker, who co-ordinated all communications with Aboriginal people and Communities regarding introduction, progress and review of the project. Ongoing consultation assured informed and mutual understanding of the research process during data collection, whilst respecting Aboriginal knowledge systems and recognising the diversity and uniqueness of each community and its individuals. Stories and sources of information are only used in publications with the permission of the person and the community involved.

The interviews were conducted in four geographical areas in the Northern Territory: East Arnhem Land (Maningrida,

Millingimbi, Elcho Island, Nhulunbuy, Yirrkala, Angurugu), Katherine Region (Borrooloola, Ngukurr, Katherine), Alice Springs and Darwin. As the following Australian Bureau of Statistics¹⁴ figures demonstrate, the populations in these areas are small and thus the seventy-two interviews completed for the research represents consultation with a substantial portion of individuals in the area.

Table 1: Demographics (Indigenous populations in parenthesis)¹⁴

East Arnhem Land	Katherine Region
Maningrida: 1,645 (1,366)	Borrooloola: 824 (494)
Millingimbi: 992 (918)	Ngukurr: 933 (844)
Elcho Island: incorporated with Galuwinku 1,463 (1,346)	Katherine: 8,610 (1,568)
Nhulunbuy: 3,804 (275)	
Yirrkala: 648 (493)	
Angurugu: 822 (721)	
Alice Springs: 26,229 (3,474)	Darwin: 68,516 (5,957)

Because of the small population base for the areas from which participants were enrolled, full details of participants cannot be given for confidentiality reasons. It will suffice to report that there were a total of seventy-two (n=72) interviews completed with a wide range of participants in the above named areas including patients (n=10), carers (n=19), Aboriginal health care workers (n=11), health care workers (n=30) and interpreters (n=2). For the purposes of this article the term Aboriginal health care worker refers to a worker in health care who is Aboriginal.

Data Collection

Data were collected by conducting interviews with Indigenous clients and service providers in the participating communities. It is important to note that all of the data was collected by a respected Aboriginal Health Worker skilled in palliative care. An interpreter was used if the participant spoke in their local language.

Data Analysis

The interviews were audio-recorded and transcribed verbatim. The language texts were then entered into the QSR NUD*IST N5 computer program and analysed thematically. A phenomenological approach was taken to the recording and analysis of the data. The aim of phenomenology is to describe particular phenomena, or the appearance of things, as lived experience.¹⁵ The process is inductive and descriptive and seeks to record experiences

from the viewpoint of the individual who had them without imposing a specific theoretical or conceptual framework on the study prior to collecting data.¹⁶ All of the participants' comments were coded into free nodes (files or codes in the NUD*IST computer program that are labeled and store similar language texts on one specific topic), which were then organised under thematic headings. The coding was established by an experienced qualitative researcher and completed by a number of research assistants. There was complete team member agreement on the coding and emergent themes.

It is important to note that there is no identifying information associated with any quote from any of the participants as strict confidentiality was promised to all the participants in this study. Reassurance of strict confidentiality was an imperative for this study for two special reasons. First, strict confidentiality is essential due to the sensitive nature of the cultural information provided by participants and second, confidentiality is important because of the small size of the communities from which data were collected, with the consequence that any information about a participant can potentially lead to identification.

THE SEVEN PRINCIPLES

The following discussion considers the seven principles posited by the participants as important for health professionals who are working with Aboriginal peoples during end-of-life care. These principles are as follows:

1. equity;
2. autonomy/empowerment;
3. trust;
4. humane, non-judgmental care;
5. seamless care;
6. emphasis on living; and
7. cultural respect.

Throughout the discussion, statements made by the participants in the course of the interviews are provided to exemplify what is meant by each principle and to indicate why participants consider the principle important. The discussion of each principle is situated in the relevant literature. In consideration of the limitations in terms of length of the article, the usual format of Results and Discussion has been replaced by a structure that deals separately with the findings, discussion and literature relevant to each principle in turn.

Throughout the discussion, the Indigenous word 'balanda' refers to the East Arnhem Land term for non-Aboriginal person. The term is thought to have originated from the Indonesian word 'hollander' or 'ballander' as it refers to the

early Dutch traders who sailed down from Indonesia to Arnhem Land on the annual monsoon winds.^{17,18} It is thought to be predominantly an East Arnhem term, although there is evidence that it is used throughout the Northern Territory.^{17,18}

The words of Indigenous and Aboriginal peoples are used interchangeably in the article and infer a respect for the cultural diversity of Indigenous Australian culture which comprises a broad range of distinct cultural groups with distinct cultural practices, traditions and laws.⁷ The holistic notion of palliative care, as applied to work with Indigenous Australians, is outlined by the National Palliative Care Program (NPCP)⁷ as:

“Palliative care is the care provided to a person whose disease is terminal and not responsive to curative treatment. It recognises the special needs of a person with a life threatening illness. These needs may be cultural, spiritual, emotional, psychological, social and /or physical. A holistic approach to palliative care also recognises the support needed by the person’s family and, for many Indigenous Australians, their community as well.”

Principle 1 – Equity

The first principle is the democratic right of equal access to services that is enshrined in the notion of equity. This notion was clearly expressed in the following statement:

“I feel passionate – I’m balanda but I feel passionate about rights of equity to service delivery. It doesn’t matter where you live in the country, we all have rights to service delivery that should be equal.”

One of the chief obstacles to equity of access is the fact that most of the services are concentrated in towns and urban areas. This is particularly so with respect to palliative care services:

“A lot of the issues we have with palliative care are there are so many services available for people in the main towns, Darwin city, that aren’t available in the communities to help family better look after people who are dying and to make them more comfortable.”

Unfortunately, in relation to Aboriginal health there are still significant equity problems, as is evidenced by the fact that Australian Aboriginal people who get cancer are twice as likely to die from it.¹⁹ However, as Condon et al²⁰ argue,

beginning to understand and document the issues at the interface of Aboriginal and Western culture is an important step in addressing the inequity of the difference in cancer survival.²⁰

Principle 2 – Autonomy and Empowerment

The second principle participants noted as underlining the philosophy of health care is the principle of autonomy – the importance of ensuring that individuals are encouraged to take control of their own illness experience. It was stated that the focus of palliative care should be on the rights of people to make fundamental choices, with the family and health care professionals’ task being to implement and support their choices.

“Our first brief is to make sure that people take control of their illness in whatever way they want. We try to explain to people that it is really their decision in the end with their life.”

In particular, palliative care is seen as being instrumental in providing individuals with choices that deflect increasingly aggressive treatments.

“I think that the palliative care movement has done some really good stuff in that once upon a time everybody was shuffled off for fairly aggressive treatment. It didn’t matter where you were, but now there is a degree of humanity that comes into it and choices come into it.”

As outlined and detailed elsewhere,²¹ the notion of choice for an Indigenous patient is not individualist or atomistic, as it is with Western culture, but is instead based in family and community relationships. Thus, to respect choice for Indigenous people, it is important to share information with the network of appropriate people in the family and community through communication processes such as family meetings. As one participant stated:

“... in which case we think it’s important to have meetings with the family... the client and the health center and anybody else.”

It is important to respect the Indigenous cultural rules for information-giving to ensure that Aboriginal people have the knowledge to make autonomous choices.²¹ This involves ensuring that the “right story” is given to the “right” people within the family network of the Indigenous patient.²¹

“Helping getting the right story for the family or that sick person so they can make the right

choice ... I think they have to make that decision in the community away from all the other pressures."

Participants provided examples of the different possibilities of choice that are available in relation to palliative care to demonstrate this principle in practice, for example:

"... just to let that person have control over what they want to do... the sorts of things that are important to them... what he wanted most of all was to come back and be with his family and out on his outstation."

In view of the sense of disempowerment with mainstream services, advocacy is important for expressing choice for many Aboriginal patients and their families.⁷ The culturally appropriate people to support Indigenous peoples in their choices can include an Aboriginal Health Worker (or Liaison Officer), an Elder or Indigenous Australian community leader, a trusted friend or a community member.⁷

Principle 3 – The Importance of Trust

The importance of trust needs to be set in the historical context of colonialisation.

"And I think because of the history, the contact history, there is still a feeling of not being completely safe..."

It was noted that Indigenous peoples still have to deal with ongoing oppression.

"The way that balanda treat (name of Indigenous people) all the time, in the school, at the counter, the clinic, wherever, balanda are always saying: this is the way to do this. They've always got the ideas the balanda, the balanda is always talking and [there is] little chance for the (name of Indigenous people) to be involved. It's always in English and the balanda ideas are always right and that gives people a feeling of not being accepted, [of] being powerless."

The National Palliative Care Program (NPCP) record three significant oppressive processes from past Australian government policies that have contributed to the breakdown in Indigenous Australian culture in the publication, *Providing culturally appropriate palliative care to Indigenous Australians: Resource Kit*.⁷ The processes are: forced relocation from traditional lands; the taking of mixed race children (the stolen generation); and the lack of rights and decision-making

power. NPCP notes that these events, and the results of the policies underpinning them, are still very vivid in the minds of many Indigenous Australians and as a consequence many have little trust in mainstream health services.⁷

Particularly for remote Indigenous peoples, the fear generated by the history of oppression is exacerbated by the fear associated with the alien and often invasive practices of Western medicine.

"This person said, and they're going to administer those drugs to someone to kill them. And other might say: come on, that's ridiculous. But the fact there are a group of people discussing it and giving credence to that gives this message of yes, there are people who don't feel secure. And I know many people who are absolutely fearful of being in Intensive Care Units, won't get out."

The lack of trust is in part caused by a lack of understanding of Western medicine.

"Sometimes they can trust balanda medicine, sometimes not, because sometimes people doesn't know what that kind of medicine's doing."

As Maher²² explains, there is poor compatibility between the underlying values of the Western medical system and the traditional Aboriginal beliefs. However, as documented elsewhere,² Aborigines often make their own accommodation between the conflicting Indigenous/Western world views on health and healing and sometimes hold both belief systems without endorsing all aspects of either. Blackwell²³ recognises the need for a cultural understanding of 'parallel issues' where Indigenous people will seek 'white medicine' while pursuing traditional strategies of healing.

Throughout the data there is an emphasis on the importance and efficacy of developing service delivery through establishing trusting relationships. As one participant summarised the principle:

"... everything is relationship-based and they wouldn't be talking to a stranger."

Health professionals gave descriptions of the process of trust building, which can take months or years.

"I've been going out now regularly for a year or so they get to know you and then you get to know their families and if someone is really sick

it is a way of getting a foot in the door.”

In essence, trust building with the Indigenous community is about having a continuing and face-to-face presence.

“You don’t gain Aboriginal trust by not being around them all the time, you have to be. Your face has to become familiar with them.”

It was also noted that it is essential to honour promises.

“And if you promise to do something for them then you must do it and you must fulfil your promise, you can’t back out half way. So I found that out over the years by always... If I come here and they want something I go back to town and we haven’t brought it out with us I make sure it comes back.”

The process of building trust can be slow and take many years. The turnover of staff can also therefore, interfere with the process of building trust.

“So you slowly... they slowly going to get to trust you. So it comes down to that: having a relationship with Aboriginal people. And I mean with clinics now there are not many clinics that we have that have the stabilised staff that we used to have years ago.”

Any breach of trust can cause a breakdown in relationships that will interfere with the success of future work.

“Breaking down relationships... They might come into contact with that family again somewhere else and they’ve already established that you can’t trust that person so it can ‘dog’ her work.”

As Maher²² strongly argues, it is vital for health professionals to develop skill in communication across cultural differences, as trusting relationships with Aboriginal patients are essential for the provision of any treatment.

Principle 4 – Humane, Non-judgmental Care

The fourth principle of health care that was clearly articulated in relation to palliative care services for Aboriginal peoples is that of humane, compassionate, non-judgmental care. It was noted that part of the ‘job description’ for health professionals is to extend themselves to provide compassion to sick individuals with an accepting attitude that allows individuals the comfort of being responded to, rather than

judged.

“In palliative care when people are dying (and they) get cranky and crabby, they will abuse you. We are not here to growl at anybody - if they request a beer they can have a beer. If they want to smoke (even though) dying of lung cancer, then grant (that) last wish. You are showing (an) act of kindness, a humane thing to do. (It is) important to keep peoples feelings in consideration, to try and make their stay happy, in a friendly environment. This is our job to care.”

Part of the expression of that humane care includes the palliative care focus on quality of life, where aggressive treatments can be avoided for the sake of comfort.

“And I would ask the doctor, why do I have to go and inflict another blood test on this person when we know that they’re dying and we should be just trying to make it as comfortable as possible?”

Compassionate, non-judgmental care is the cornerstone of palliative care, with the very notion enshrined in clauses found in the Dying Patient’s Bill of Rights, such as ‘I have the right to retain my individuality and not be judged for my decisions which may be contrary to the beliefs of others’.^{24,25}

Principle 5 – Seamless Care

The fifth principle articulated by participants is that of seamless care. This involves the collaboration of the multi-disciplinary mix of health professionals from a variety of in-patient and community-based organisations that work together on the continuum of care for the patient and their family. Such seamless care involves sensitive psycho-social care and skilled clinical care.

“It is seamless - we are very lucky here with the calibre and professional attitude of the staff in that when something happens they really pull out all pins to go the extra distance. All focused around the right of people to make fundamental choices, people of the family and the responsibility of the health centre together with palliative care to put it in place.”

The comprehensive response to the individual’s needs is termed holistic care and is based on a multi-disciplinary plan of care addressing the physical, spiritual, social and

emotional needs of each patient and their family.²⁶ Sullivan and associates¹⁶ work on Indigenous palliative care affirms the importance of flexible and responsive services to allow patients and their families to choose the options they want and to change their minds if the situation requires it. NPCP's guidelines for Indigenous care emphasise the fact that palliative care is a collaborative discipline which involves a multi-disciplinary team, all of whom recognise the Indigenous Australian, their family and their community as the unit of care.⁷

Principle 6 – Emphasis on Living

It was noted that a strong palliative care principle of quality of life, or emphasising the living rather than the dying, is an essential ingredient of end-of-life care.

“But that is after all what it is about - Living when you are dying, really.”

The emphasis on living is enshrined in all palliative care literature and was originally articulated by the initiator of the movement, Dame Cicely Saunders, when she wrote:

“A patient should be enabled to live until he dies, at his own maximum potential, performing to the limit of his physical activity and mental capacity, with control and independence where ever possible.”²⁷

Principle 7 – Cultural Respect

There were many instances where participants spoke of the profound distress that Indigenous peoples experienced in relation to the disrespectful way they are dealt with by some ‘balanda’ health professionals. Thus, one of the strongest recommendations is for the notion of respect to permeate all dealings with Indigenous peoples. The principle of respect is particularly important in relation to cultural practices and beliefs, as the following text illustrates.

“The right people to handle the body, I’m always respectful of that. And there again we had problems with some of the nurses rushing in or police wanting to, you know, wrap the body up and just take it away. And I think it is the respectful thing to do (waiting for the right people to handle the body) and I don’t have any objections to the health truck being painted with ochre either. I think all those sort of things build health relationships between the clinic and the community because people know that you respect.”

Another demonstration of cultural respect was provided in the description of the care provided to a tribal elder who was a medicine man.

“We had an old man that came and he was a traditional tribal elder, no females allowed in the room, he had a male carer, no female nurses were allowed so I asked only for males in that room. Nobody was to look upon his face. So we made sure all of that was in place, even when he come into the room he was shielding his face. The carer came out and said no females allowed. So we respected his rights for that.”

As Fried states, culturally-based considerations of lifestyle, beliefs and values for Australian Indigenous people assume increased significance in palliative care.²⁸ Similarly, research on other Indigenous groups such as native American elders and Canadian Aboriginals indicates that culturally appropriate care should be predicated on the notion of power sharing, where respect is given to those with cultural expertise and the ethical authority to direct understanding as to how to engage in culturally appropriate actions.^{28,29,30} In the 1980s the term “cultural safety” was coined in relation to nursing care for people of Maori culture in New Zealand and is now widely accepted as a baseline for establishing relationships of cultural respect. The notion of cultural safety, the core of the seventh principle, is defined as follows:

“The effective (health care) practice of a person or family from another culture is determined by that person or family. Culture includes, but is not restricted to, age or generation; sexual orientation; occupation and socio economic status; ethnic origin or migrant experience; religious or spiritual belief; and disability. The (health practitioner) delivering the nursing will have undertaken a process of reflection on his or her own cultural identify and will recognise the impact that his or her personal culture has on his or her professional practice. Unsafe cultural practice comprises any action which diminishes, demeans or disempowers the cultural identity and well being of an individual.”³¹

CONCLUSION

The seven principles outlined in this paper have been gleaned from the collaborative wisdom of a wide range of Aboriginal peoples and the people who care for them throughout the Northern Territory. As the principles have now been reviewed and affirmed by a diversity of national

audiences, it is with confidence that the authors offer them as a practical starting point for ensuring that excellence in end-of-life care is provided for Australia's first peoples. In so doing, it is also the authors' hope and expectation that the principles will provide insights for others working with Indigenous peoples around the world.

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