Insights from the Northern Territory on factors that facilitate effective palliative care for Aboriginal peoples

Pam D McGrath and Emma L Phillips

Abstract

This article aims to assist remote communities to develop their own palliative care services by providing findings on successful strategies identified through a 2-year research project which developed an innovative model for Indigenous palliative care. The discussion is set in the context of an understanding of the notion of cultural safety and discusses the positive experiences of the benefits of palliative care from the perspectives of both consumers and health professionals. The findings show that successful outcomes are derived from generic factors associated with palliative care philosophy and practice and from more specific factors, including the provision of pragmatic support to overcome practical problems, and community visits by health professionals. Factors specific to cultural respect are important, including familiarity and continuity of health care providers, cultural respect for grieving practices, provision of comfort food and bush tucker, development of culturally appropriate built environments, use of traditional healers and respect for spiritual practices.

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What is known about the topic?
Australian Aboriginal peoples have very high rates of mortality and premature death. Consequently, the provision of palliative care is seen as critical for Aboriginal peoples, however palliative care services are not well established in Aboriginal communities.

What does this paper add?
The findings provide insights from a wide range of health professionals and consumers on processes that have been observed to contribute to best-practice end-of-life care for Aboriginal peoples in the Northern Territory.

What are the implications for practitioners?
Health care workers talk about ways to provide palliative care to Indigenous peoples, with successful practices including familiarity and continuity of health care providers, cultural respect for grieving, provision of comfort food and bush tucker, development of culturally appropriate built environments, use of traditional healers and respect for spiritual practices.

AUSTRALIAN ABORIGINAL COMMUNITIES live with the consequences of losing their land, their culture, their autonomy and, in many cases, their language, their dignity and their health.[1-3] Serious and ongoing problems in relation to Aboriginal

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health are well documented.[4-6] In addition, much has been written about the problems of health care delivery in rural and remote areas, and how these issues are compounded by the cultural, linguistic and socioeconomic barriers unique to Aboriginal communities.[5,7]

Australian Aboriginal peoples have very high rates of mortality and premature death;[5] indeed, the death rates for Aboriginal Australians are among the highest in the world. Consequently, death and dying is a very relevant issue for Aboriginal communities in all parts of Australia,[1,8] and palliative care is seen as critical for Aboriginal peoples. However, as yet, palliative care services are not well established in Aboriginal communities.[1]

For many good reasons, the literature emphasises the deficit in Aboriginal health and palliative care services through a focus on what is going wrong. White and associates[9] refer to this

as the "needs and deficits" discourse which draws attention away from developing a body of remote area palliative care knowledge. Importantly, these authors argue that such a view of remote cultures has shifted attention away from an examination of the real capacity of remote communities to aid in developing their own palliative care services. This article affirms this perspective and seeks to contribute to a reversal of the predominant focus in the literature on negative outcomes. Thus, this article provides findings on successful strategies identified through a 2-year research project, funded by the National Health and Medical Research Council (NHMRC), which aimed to develop an innovative model for Indigenous palliative care. This objective has been achieved and the model is now available.[10] The findings from the study presented in this article cover insights from a wide range of health professionals and consumers on processes that have been observed to contribute to best-practice end-of-life care for Aboriginal peoples in the Northern Territory. It is hoped that sharing the generous insights provided by the participants in the study will provide useful insights for health professionals who care for Aboriginal peoples during the time of death and dying.

The following discussion is set in the context of the notion of cultural safety, which is a concept developed by Ramsden[11] in the nursing education setting in New Zealand as a response to colonising processes in Aotearoa/New Zealand.[12] The notion of cultural safety involves the recognition of the social, economic and political position of certain cultural groups within society.[11,12] As Smye[13] argues, the notion of cultural safety reminds us that we are all bearers of culture and that culture influences the care we provide. It is a practice that respects, supports and empowers the cultural identity and wellbeing of individuals.[14]

Methods

The data were collected through open-ended, qualitative interviews with a cross-section of participants (consumers and health professionals) throughout the Northern Territory. The model was assessed by a national peer-review panel of experts in Indigenous health and a meeting of the Northern Territory Aboriginal Reference group. The model and the seven principles which form the foundation for the model (equity; autonomy/empowerment; trust; humane, non-judgmental care; seamless care; emphasis on living; cultural respect) have been affirmed by a wide range of national and international audiences. The qualitative data collected were extensive and rich. The findings under discussion in this article refer to the data on the practices contributing to successful outcomes in relation to end-of-life care of Aboriginal peoples in the Northern Territory.

Ethics clearance

This project was conducted in compliance with the NHMRC *Guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research*[15] and the Australian Institute of Aboriginal and Torres Strait Islander Studies' *Guidelines for ethical research in Indigenous studies*.[16] Permission and authorisation was obtained from a number of research ethics committees: the Human Research Ethics Committee of the Northern Territory Department of Health and Community Services (formerly Territory Health Services); the 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 before participating in the project. The project is mindful of factors associated with cultural safety and consistent with guidelines for Indigenous research as outlined by such bodies as the Cooperative Research Centre for Aboriginal Health in terms of intellectual property, dissemination, ethics, partnerships, and implementation (http://www.crcah.org.au/research/approachtoresearch.html).

Demographics	
Region	Total population (Indigenous population)
East Arnhem Land	
Maningrida	1645 (1366)
Millingimbi	992 (918)
Elcho Island incorporated with Galuwinku	1463 (1346)
Nhulunbuy	3804 (275)
Yirrkala	648 (493)
Angurugu	822 (721)
Katherine Region	
Borroloola	824 (494)
Ngukurr	933 (844)
Katherine	8610 (1568)
Alice Springs	26 229 (3474)
Darwin	68 516 (5957)
Source: Australian Bureau of Statistics 2001 census data.[18]	

Research focus

The research questions included:

- What palliative care services are provided and are they meeting the clients' needs?
- How can the services be modified to deliver a culturally appropriate, innovative and exemplary model?
- 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",[17] 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 peoples during the end-of-life trajectory.

Participant group

The research team included an Aboriginal health worker, who coordinated all communications with Aboriginal peoples and communities. Ongoing consultation assured informed and mutual understanding of the research process during data collection, while 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 (Borroloola, Ngukurr, Katherine), Alice Springs and Darwin. As the Australian Bureau of Statistics figures demonstrate,[18] the populations in these areas are small (Box 1).

Because of the small populations of the areas from which participants were enrolled, full details of participants cannot be given for confidentiality reasons. There were a total of 72 interviews completed with a wide range of participants, including patients (10), carers (19), Aboriginal health care workers (11), health care workers (30) and interpreters (2).

Data analysis

The interviews were audio-recorded and transcribed. The language texts were then entered into the NUD*IST N5 computer program (QSR International Pty Ltd) 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.[19] 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 before collecting data.[20] The coding was established by an experienced qualitative researcher and completed by a number of research assistants for the project. There was complete team member agreement on the coding and emergent themes.

There was no identifying information associated with any quotes from participants. Strict confidentiality was promised to participants in this study because of the sensitive nature of the cultural information provided by them, and given the small size of the communities and the likelihood of identification.

Findings

In the following discussion the Indigenous term "balanda" refers to non-Aboriginal or European people. 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.[21,22] It is thought to be predominantly an East Arnhem term, although there is evidence that it is used throughout the Northern Territory.[21,22] In the following quotes, the reference to TPC stands for Territory Palliative Care.

Positive experiences

Positive feedback on the benefits of palliative care was provided by the full range of participants, including patients and health professionals, as the following examples show:

> Palliative care very, very good, it was really helping me; everyone coming in and helping me.

> I am [health care position] and happy to say that I am very pleased with the palliative care program out of Darwin.

The gratitude and high praise inherent in the comments is demonstrated in the following statement about available palliative care services:

> They actually help us to help and they're just brilliant. What we'd do without them I don't know. We have 24 hour access to pal care which is just brilliant, there is always someone on call for us to refer to if we need to and I actually think they do a brilliant job here, I can't think of much that I could suggest that would make the system work better.

Factors generic to palliative care philosophy and practice contributing to success

Many of the insights provided by participants referred to generic factors associated with palliative care philosophy and practice. As one participant remarked about the success of the palliative care movement:

> 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 and that pleases me.

The participants discussed the importance of a range of practices that are at the core of palliative care service provision and are determinants of satisfaction with palliative care in a diversity of settings. These factors included: a focus on living; respect for choice and autonomy; patient advocacy; provision of support; patience and compassion; multidisciplinary skill; 24-hour back-up; expert advice; interagency cooperation; seamless care; dedicated professionalism; carer upskilling; and provision of respite care. The positive recognition given to generic palliative care practices is accompanied by an awareness of the benefits of palliative care education and training. Batchelor College (now Batchelor Institute) in the Northern Territory was specifically mentioned as providing leadership in this regard.

As the discussion will now elaborate, the participants also mentioned a number of factors that were more specific to palliative care service delivery for Aboriginal peoples.

Factors specific to rural and remote locations contributing to success

As outlined in detail elsewhere,[23] one of the defining obstacles to palliative care provision for Aboriginal peoples is the sheer magnitude of the practical problems that need to be addressed. Consequently, participants were full of praise for practical assistance that helped to overcome these difficulties. At an elementary level, assistance in finding a bed for the patient was particularly valued, as the following statement demonstrates:

> [TPC] have offered us through the palliative care program in Darwin more than helpful in regards to trying to get a bed for someone out in the community.

Furthermore, provision of practical items that enhanced the comfort of the patient was

described as being of utmost importance to palliative care patients. For example, air conditioning was considered to be greatly beneficial to vulnerable, terminally ill patients, because of the consistently high temperatures experienced in the Northern Territory. Provision of simple necessities was also significant, as the following response demonstrates:

> The other thing the palliative care service does is that they seem to go out of its way to provide equipment and simple necessities like bedding and stuff like that, shower chairs, which aren't readily available in the community at short notice.

This is particularly helpful in circumstances where local resources would preclude the attainment of such items, as the following statement shows:

> If need special equipment tap into palliative care in Darwin. Need permission from client — entitles them to lot of things that would cost them an arm and a leg, a fortune. If the bed too low, TPC will ship bed down. If need frames, oxygen concentrator — it doesn't cost the client. TPC, Darwin pay the whole lot.

A range of organisations contribute to the provision of equipment, as the following statement demonstrates:

> For bed linen I tap into hospital. For sheep skins I go to community health. For bed pan tap here — community connections.

The provision of equipment is seen as directly creating the opportunity for Aboriginal peoples to stay in their own home during the terminal stage, as the following response illustrates:

> Equipment's good we get great service from palliative care. Recently [TPC] provided infusion pump for another Aboriginal man. If they didn't come up with that equipment so quick that wouldn't have happened for that old man. All he wanted to do was go home, they certainly made it happen there.

Health professionals talked about the flexible and creative approach they needed to take to ensure practical problems are overcome:

> [Getting oxygen to old man] That was big . . . Just to get the generator now needs to run 24 hours and that [oxygen] not happened anywhere out in a homelands before. We've paid for the petrol for that to happen for the next couple of months. After that we don't know what is going to happen but it has been a success. It will continue to happen. So it is those difficult things that they don't — they are hard to organise I suppose.

References to practical support did not just refer to equipment but also covered organisations such as Meals on Wheels who ensure patients have food. Additionally, the participants praised initiatives that helped out with activities such as shopping and transport, as the following statement shows:

> They've just recently got some funding from the Commonwealth for aged care packages through the outstations resource centre and we identified 10 people from outstations. Some of them have pretty nasty respiratory diseases and that's the helping them do things like go somewhere for shopping, go somewhere they can go hunting — things like that.

Visitations by health professionals to communities

There is a lack of local palliative care services throughout the Northern Territory, so health professionals who travel out to the communities are greatly appreciated.[24] The aged care team were specifically mentioned in this regard:

> Aged care team are good with that because they all got communities each that they constantly visit and nine out of 10 days they are out bush so they are great for feedback and they often ring and say that they seen so and so out bush and let me know how they are going if there is anything that is needed.

Also, TPC were seen as accessible and prepared to travel to the communities:

For emotional support for family tap into Darwin. Palliative care mob has pastoral care support that would come down to talk to them. TPC come down quite often.

Factors specific to notions of cultural respect contributing to success

The literature has clearly established the benefits of the development of trusting relationships when working with Aboriginal peoples.[25] For this reason, health professionals who work in the same area for a prolonged period of time provide familiarity and continuity and thus make a substantial contribution. As one health professional explained:

> Now that she's been around and she's had to come into the clinic a few times with bad chests and stuff, and she's sort of seen I'm not so bad after all, she's sort of got used to it.

When working with Aboriginal peoples it is important to understand and relate to the broad family and community networks.[26] Thus, health professionals who stay in the same position for a significant period of time make a substantial contribution to the experience of Aboriginal palliative care patients and their families, as the following statement demonstrates:

> Yeah, got to know a lot of people. And I feel that I can walk around the community now and go and talk to families that I've met in Darwin and they're quite happy to sit down and talk with me. I mean not many people stay in those jobs long enough and to me that's a big issue.

Cultural respect for grieving practices

There are a number of well defined ceremonial practices which often involve the intense and open expression of grief. Health professionals who understand and respect these cultural practices are instrumental in bringing about successful outcomes. A description of such respect is:

> [With respect to wailing and crying] they do, we usually give them as much time as they want to stay with their loved one and they do wail or they will sit outside and sit in a group. It is more like humming than wailing and we have had one family that wanted to smoke the room afterwards. We have our palliative care unit set up like a home that they can come in and family can sleep and stay with them. And it's got an area out there where all the family can meet. It is self sufficient with tea and coffee and meal supplied for one person that stays, you know, full-time.

Participants indicated that successful outcomes are assisted by providing comfort and traditional foods to the Aboriginal patient, as the following response shows:

> Give chicken and sweet corn [as it is] easy to swallow ... [when they can't swallow] we get chicken and sweet corn and we give it to the patient. All can swallow it. Or honey, bush honey, mango ones.

There were indications that some facilities had specially prepared the physical environment to meet the cultural needs of Aboriginal peoples. As the following statement outlines, this not only involves ensuring that rooms are large enough to accommodate the extended family network who traditionally gather when someone is dying, but also that there is a view to the outside environment, which is essential for Aboriginal peoples.

> [Interviewer: I like the set-up you've got here with one big room close to the exit area.] It used to be that if anyone was grieving in there the only place they had was to come out on the main veranda with everybody else from the ward as well. If they wanted to have a cry it wasn't very private so we've had an area built out in the other side, a little garden area with a table and chairs that they can go outside there by themselves and have their little cry if they want to. There is heaps of room for a family.

Use of traditional healers and respect for spiritual practices

As outlined in detail elsewhere,[10] traditional Aboriginal peoples have a different perspective on

health and healing. Findings on successful outcomes indicate that health care professionals who respect Aboriginal spiritual practices and integrate bush medicine and traditional healing build strong connections with Aboriginal peoples. One participant explained the steps taken to ensure Aboriginal spiritual and traditional practices were respected, as follows:

> The other part we make sure [of] too [is] that the witch doctors or medicine people see the old people; that they've got access to that. We even suggest it to people so that we have a combination of balanda or Western medicine plus cultural medicine. The other thing is we also encourage use of bush medicines as much as possible. Plus fellowship, church or spirit — other ways of things so the whole three, we work together in that way.

Discussion

The findings from this study provide a loud acclamation to the success of health professionals working to provide best-practice end-of-life care for Aboriginal peoples in the Northern Territory. There is some awareness of the important contribution that the palliative care movement has made to the care of the dying. Much of the discussion of positive outcomes was directly related to palliative care practice. In particular, participants made positive references to the significance of the palliative care focus on living, respect for choice and autonomy, patient advocacy, provision of support, patience and compassion, multidisciplinary skill, 24-hour back-up, expert advice, interagency cooperation, seamless care, dedicated professionalism, carer upskilling and provision of respite care. An awareness of the positive contribution of such practices was accompanied by a valuing of educational opportunities which focused on the provision of quality care. This finding resonates with the Australian work of McConigley and associates[27] that indicates that rural health professionals would welcome increased access to both education and support services when providing palliative care to patients in their communities.

There was extensive evidence that health care workers were successfully finding ways to deal with the major practical problems associated with working in rural and remote locations. Praise was given to the wide range of organisations that are presently meeting practical needs by providing a diversity of equipment including air conditioning, beds, linen, bed pans and shower chairs. This is especially helpful when costs are kept to a minimum. Creative and flexible approaches were documented to challenges such as the provision of oxygen and maintenance of generators in rural and remote locations. In addition, it was noted that practical assistance in the form of help with shopping and transport and provision of meals makes an important contribution. In view of the major problems caused by the lack of local services,[24] however, a core finding is the significant positive contribution made by organisations that are prepared to visit local communities and to bring service delivery out to the rural and remote areas. This is particularly important to Aboriginal peoples during the dying trajectory, as most wish to return to the homeland to die or to be buried.[1,28,29]

It is well documented that health professionals often experience difficulties providing care to Aboriginal peoples because of the cultural distance between mainstream culture and Aboriginal culture, particularly with regard to health belief systems.[30] The findings provide insights as to the key role of cultural respect in ensuring positive outcomes when working with Aboriginal peoples. As Lowenthal and associates[5] point out, respect and understanding must be reciprocal for people with such strong spiritual convictions as Aboriginal Australians; medical practitioners dismissive of time-honoured traditions may be unable to gain their patients' trust. Health professionals who remain in the same locality over time are seen as providing the familiarity and continuity that is essential to building trusting relationships with Aboriginal peoples. That trust is affirmed with culturally respectful health care practice based on an understanding of Aboriginal kinship and community communication and information-giving

processes. During end-of-life care, the need for cultural sensitivity was especially noted in relation to respect for grief practices, the provision of comfort foods and bush tucker, the integration of bush medicine and traditional healers and respect for Aboriginal spiritual practices. As Sheldon[31] notes, strong kinship networks, hunting, bush tucker, ceremonial "business" and "sorry business" (grieving rituals) continue to play a major part in the lives of rural and remote Aboriginal communities. Maher[30] explains that, for Aboriginal peoples, treatment generally involves the use of bush medicine for specific symptoms, with traditional healers being required to deal with any matter thought to have occurred because of supernatural intervention.

There are a number of factors documented in relation to the positive role of traditional healers for Aboriginal peoples with illness, including the fact that they share a common language and world view with the patient, there is an expectation of relief from the patient, the patient receives treatment in a familiar, supportive, non-threatening environment and there is usually already a close relationship between the healer and the patient with resultant faith in the healer.[30,32,33]

Also noteworthy from the findings are the health care facilities that invested effort into specially preparing the physical environment to meet the cultural needs of Aboriginal peoples, with patient rooms situated close to exits, large meeting rooms, external areas for gatherings and provision for family members to stay overnight.

Conclusion

The insights generously provided by a diversity of participants throughout the Northern Territory provide testament to the exceptional work carried out by dedicated health professionals to provide high quality end-of-life care to Aboriginal peoples in the Northern Territory. It is our hope and expectation that these findings will be used to highlight the strengths of those involved in the rural and remote areas in the care of Australia's first peoples.

Competing interests

The authors declare that they have no competing interests.

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