

# The case for Aboriginal Health Workers in palliative care

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## Abstract

**Objectives:** The findings are drawn from 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. The findings presented in this article explore one important strategy for putting Aboriginal families and their communities at the centre of the model: that is, the employment of Aboriginal Health Workers (AHWs) in relation to the provision of palliative care in the Northern Territory.

**Methods:** The data were collected from 72 qualitative interviews conducted throughout the regional, rural and remote areas of the Northern Territory with Indigenous patients and carers in the Northern Territory and the health professionals who care for them.

**Results:** While highlighting the valuable role of AHWs, the findings emphasise that the current lack of availability of such workers for palliative care provision for Indigenous peoples needs serious consideration.

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## What is known about the topic?

Often culturally sensitive health care is not available to meet the needs of Indigenous patients. This is a particular issue for palliative care services.

## What does this paper add?

This paper outlines the qualitative data from 72 interviews of patients, carers, Aboriginal health workers, health care workers and interpreters in the Northern Territory. The study affirmed the importance of Aboriginal Health Workers in the provision of palliative care.

## What are the implications for practitioners?

Health policy makers and service providers should ensure Aboriginal Health Workers are available to provide palliative care services in Aboriginal communities.

INDIGENOUS AUSTRALIANS face significant obstacles in accessing health services, many of which are created by cross-cultural barriers between Aboriginal culture and Western medicine.<sup>1</sup> The cultural differences between the dominant Anglo-Australian group and the Aboriginal Australian group are significant, particularly in relation to disease and death.<sup>2</sup> Aboriginal health is not just about the physical condition of the body, but embraces spiritual notions of the family and community that many Western models of health care delivery fail to identify and, therefore, accommodate.<sup>3</sup> As McConnel<sup>4</sup> recommends, strategies are needed to facilitate the sharing of knowledge at the interface of Western medicine and Aboriginal culture, in a way that includes Indigenous beliefs and practices.

Research affirms that health care models that put Aboriginal families and their communities at the centre of the system and allow them control have had dramatic success in improving access to care, and ultimately the health status of Indigenous communities.<sup>5</sup> The findings presented in this article explore one important

strategy in this regard: the employment of Aboriginal Health Workers (AHWs) in relation to the provision of palliative care to Indigenous peoples. The findings are drawn from a 2-year research project funded by Australia's 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 in a final report.<sup>6</sup>

## Methods

The data for 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 was assessed by a national peer-review panel of experts in Indigenous health and a meeting of the project's Northern Territory Aboriginal reference group. The findings discussed in this article refer to the employment of Indigenous people, in relation to the provision of palliative care to Indigenous peoples, either as liaison staff or as AHWs.

## Ethics clearance

This project was conducted in compliance with the NHMRC Values and Ethics: Guidelines for Ethical conduct in Aboriginal and Torres Strait Islander Health Research,<sup>7</sup> and the Australian Institute of Aboriginal and Torres Strait Islander Health Research 2004, Ethical Guidelines for Research.<sup>8</sup> 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 (previously Territory Health Services) and Menzies School of Health Research in Darwin; the Central Australian Ethical Committee in Alice Springs; the Human Research Ethics Committee of Charles Darwin University (previously Northern Territory University); and the Central Queensland University. Approval was sought from relevant Community Councils (Chairs/Elders as appropriate) and from all individuals before participation in the project. A guarantee of

confidentiality for the individual and the community was assured.

## Research focus

The research questions informing the data collection included:

- What palliative care services are provided, and are they meeting the clients' needs?
- How can 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",<sup>6</sup> 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

An AHW was a participating member of the research team, and coordinated 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, while respecting Aboriginal knowledge systems and recognising the diversity and uniqueness of each community and its individuals. Stories and sources of information are acknowledged and only used in publications with the permission of the person and the community involved. This project has provided participants with the opportunity to discuss their palliative care needs, with the aim of improving end-of-life care for Aboriginal peoples.

The interviews were conducted in four geographical areas in the Northern Territory, including East Arnhem Land (Maningrida, Millingimbi, Elcho Island, Nhulunbuy, Yirrkala, and Angurugu), Katherine Region (Borrooloola, Ngukurr, and Katherine), Alice Springs and Darwin. Australian Bureau of Statistics<sup>9</sup> population figures demonstrate a relatively small total Indigenous population of 17 456, and thus the 72 interviews

completed for the research represent a substantial consultation with key individuals in the area. Because of the small population base for the areas from which participants were enrolled, full details of participants cannot be given for confidentiality reasons as individuals may easily be identified. There were a total of seventy-two interviews completed with a wide range of participants in the above named areas including patients ( $n = 10$ ), carers ( $n = 19$ ), Aboriginal health workers ( $n = 11$ ), health care workers ( $n = 30$ ) and interpreters ( $n = 2$ ). For the purposes of this article the term Aboriginal Health Worker refers to a worker in health care who is Aboriginal.

### **Data collection and analysis**

Data were collected using taped interviews with Indigenous clients and service providers in the participating communities. The interview schedules are available in the “companion book”.<sup>10</sup> It is important to note that all of the data collected were completed by a respected AHW skilled in palliative care. An interpreter was used if the participant spoke in their local language.

The interviews were audio-recorded and transcribed verbatim. 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.<sup>11</sup> 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.<sup>12</sup>

All of the participants’ comments were coded into free nodes (files or codes in the NUD\*IST computer program that are labelled 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 for the project. There was complete team member agreement on the coding and emergent themes.

As inductive, phenomenological, qualitative work, the reporting of findings is based on a commitment to the participants’ point of view with the researcher playing the role of co-participant in the discovery and understanding of what the realities are of the phenomena studies.<sup>11,13-15</sup> Thus, a narrative account dominates, with a clear separation between the presentation of the exact words of the participants in the findings section and the interpretation in the discussion section.<sup>16</sup> For economy of presentation the selected nodes have been organised under categories that, when juxtaposed, build an outline of the issues.<sup>17,18</sup>

Much of the data collection was from remote communities, and for some interviews an interpreter was used. Hence, many of the language texts are not necessarily couched in fluid English. As a compromise for readability, some of the texts have had words added in parenthesis to improve clarity of meaning. However, even with this assistance some of the texts remain difficult in expression. It was considered important not to change the texts further to stay true to the participant and keep a sense of the original word.

The data was collected by an AHW, and many of the quotes included are from Indigenous people. However, because the participants often talk in the third person about Indigenous people (for example, talk about “their culture”, “the things they do”) the verbatim text can give the misleading impression, at times, that the quotes are from a non-Indigenous person talking about Aboriginal people. It was decided to retain the original expression to avoid any change to the authentic meaning of the statements.

### **Findings**

In the following discussion the word “balanda” refers to non-Aboriginal or European people. It is an East Arnhem Land term that comes from the word “Hollander”.<sup>19</sup>

#### **Not comfortable with balanda**

Participants indicated that the Indigenous peoples’ preference for AHWs needed to be understood in the context of the cultural fear of white people and

clinical biomedicine, the importance of traditional relationships and knowledge systems, and the language barriers. Indigenous people stated honestly and clearly that they experience fear when being cared for by non-aboriginal health professionals in the hospital setting.

... when they are in hospital they actually frightened because balanda all over the places in the wards.

And especially when exposed to biomedical technology.

[They need] more support because when they [are] in the hospital lying there with no [name] looking after them, [when they have an] injection or something, when nurse or sister give him something they [are] actually frightened.

In part that fear is accompanied by a sense that Western medicine does not care about Indigenous people.

What I reckon is something the community's doctors don't care about Aboriginal people.

The findings on cross-cultural fear and incompatibility, which are complex and reported in full elsewhere,<sup>20</sup> can only be noted in this article.

### **Knowledge ownership and recognition**

The fear is exacerbated by the fact that Western clinical medicine is not seen to be respectful of traditional Indigenous understandings of healing knowledge, which includes notions of ownership.

And often more afraid of them because they don't have the understanding. I mean the whole ownership of knowledge thing is that unless that person is recognised traditionally as belonging to the knowledge of healing.

The communication of information about healing in the traditional Indigenous system depends on relationship systems with rules about the "right" individuals within the social system who are deemed appropriate to share healing knowledge.

The ownership and the right to tell the story really came clear to us that there are some

things that were not effective through using the health workers to tell the story. I mean, when we actually sat down and told the story and they helped; it was very different because people would listen to us, because we had the knowledge and that knowledge belonged to us, so therefore we were the right people to tell it.

Another factor mentioned which makes the cross-cultural situation difficult is the significant language barrier.

Aboriginal people don't want to have balanda all the time looking after them because some young or old [name location] people they can just understand small little bit of English.

### **Aboriginal workers understand their own people better**

For many reasons the presence of AHWs is perceived as a positive solution to reduce the sense of fear and alienation for Indigenous people, which is especially important during the sensitive and distressing time of coping with terminal illness. Importantly, AHWs who are able to speak in and interpret Indigenous language can assist greatly with communication.

I know having worked with nurses who've worked elsewhere and they've learnt bits of language or whatever and it really does make such a difference with the oldies. And that's where [it] would make a difference having someone around, whether as an interpreter or ...

It is noted that Aboriginal people can interpret not only the spoken but also the non-verbal language of Indigenous people.

That's right, I believe strongly in that [Aboriginal people] working with Aboriginal people can sense something that non-Aboriginal people can't — through what they say or their body language or how they look.

Also of great significance, AHWs can negotiate the disparate social and knowledge systems involved when traditional Indigenous and Western health systems interface.

One of the main roles as an Aboriginal health worker is to help be a mediator between the two systems, Western and traditional Aboriginal culture. We can have a good understanding of spiritual, cultural, social and physical needs.

Cross-cultural understanding is emphasised as the key issue where AHWs and Indigenous trained doctors and nurses can make a vital contribution.

I think we need more Aboriginal doctors and nurses, you know, but ... [it's getting Aboriginal people to do that]. Yeah and understand our way of living, our life and feelings, you know, culture and everything.

As the following lengthy text outlines about respite care for Indigenous people with a terminal illness, culturally there are complex relationship issues that need to be addressed for Indigenous people if the appointment of AHWs is to be productive.

The other problem we have with our respite is Aboriginal women working in the respite, where they can't get on with that family because the older one [will] tell you [what to do all the time] and they [are] real demanding at that stage, when they get older [and] grumpy. They want a family member working there like from that group, clan group or tribal group. [They say:] who's she and what's she doing here, she [is] not a [name of clan] or she's not a [name of another clan], they like to see [their own people looking after them from their clan]. They like to see their own people looking after them.

### **Cultural empowerment**

The idea of increasing use of AHWs in palliative care is also seen in the broader perspective of Indigenous community participation and control.

... because part of community participation and control and empowerment is employing Aboriginal people ...

Although the topic for the data collection was end-of-life care, participants indicated the need

for AHWs to be employed across the primary health care sector.

... and that can flow out into the women's centre and the crèche and all aspects of comprehensive primary health care.

### **Employment issues**

It was stressed that there is an inappropriate lack of Aboriginal employees involved in the provision of palliative care. A range of participants' statements are provided to reflect the seriousness of this concern.

It concerns me that a lot of clinics don't seem to have any Indigenous health workers at all.

Yeah for sure. There are very limited numbers of Aboriginal employees working on the wards at the bedside, whether as an interpreter or liaison officer or health worker.

I know that's what the Aboriginal liaison officers are meant to be for but there's not enough here.

There's certainly a need isn't there?

Some participants made statements to indicate that AHWs were not valued in the health system which is informed by a biomedical, clinical tradition.

There are traditions and everything and there is that perception that they really aren't all that favoured in the health system. It's all concentrated on nurses and doctors.

This is seen as a serious employment issue that needs to be addressed by government support for position creation.

Perhaps that's something the department should address because in their strategies they say that they're going to seriously address employing more Aboriginal people.

Participants not only spoke about the desirability of employing Indigenous people, but also outlined in detail the myriad of employment issues associated with recruiting and maintaining Aboriginal workers in relation to palliative care. The first issue is that of sustainability. It is noted

that the employment of local Aboriginal people for palliative care service provision would reduce the constant turnover of workers who come from outside the community.

We should first of all be looking at employing Aboriginal people and local Aboriginal people to make a sustainable service rather than people that just keep coming and going all the time.

It was noted that Indigenous people are available to complete a variety of work suitable for palliative care.

So [name location] can have [name location] people can have to work there so like house-keeper. Any people can do training and look after them.

However, even with Indigenous workers it is noted there can be turnover problems.

Unfortunately the Aboriginal health workers that we've had on the wards have found different positions, have moved on to other positions.

We got two other health workers and they've both gone into education.

Because of the small number of AHWs employed, it is considered important to ensure that support is provided in the work environment.

... sometimes because where I am situated at the hospital I am on my own ...

An important part of the provision of support was stated as ensuring that AHWs are in a work environment that understands traditional Indigenous cultural issues. A most significant issue in regard to end-of-life care is to understand the cultural imperative that Indigenous people have to attend family funerals.

So I don't always have to explain myself. I'll say to [name]: old so and so's died and the funeral's on and I'm going to it. I don't say: can I go? Or do I have to fill out a form? But I go to the funeral and then I'll go back to work, whereas other Aboriginal staff that

work, it's their culture and it's their relation or whatever [that has died], then they would just go off. And they may not come back for a week or so. And that's a lot of stuff that non-Aboriginal people just can't handle.

Flexibility and an understanding approach are considered essential in relation to funeral attendance.

I will say with the coordinator that I have, [name], she's pretty understanding with a lot of things. She never stops me or says that I'm unable to go to funerals and that.

Without such understanding the issue of funeral attendance can be the cause of staff turnover and instability.

The traditional people get in trouble if they don't go to the funeral. Yep family are in a hard place and I think when trying to get them to stay in the workforce, attending funerals is not taken into consideration. So therefore they're pushed by their family and they end up pulling out of those jobs because it doesn't support that cultural side.

### **Defining the work — role concerns**

There was considerable discussion about the actual role that AHWs could and should play in relation to palliative care. Firstly, there are descriptions from AHWs of their present role in caring for seriously ill Indigenous peoples, with an emphasis on the diversity and holistic nature of that work.

Being an Aboriginal liaison person has a very diverse and big role. I have to be mum, dad, carer, to a lot of people at different times ... do follow ups ... ask if they are coping. Do they need to come back and see the doctor ... ? I make sure that people understand because everyone has the right to know.

Others affirm such descriptions with further details of the work of AHWs as informal networking and encouraging Indigenous people to engage in health care.

Half of them haven't even set foot in the clinic; sometimes they've stayed outside,

talked to people, talked to mums and got the kids in; got the old ladies in for their checks and young women for their checks and have really been the catalyst for encouraging people to come through the health centre.

However, job descriptions are not always clear as to the specific role of the AHW, which creates confusion.

So these positions are vacant at the moment and unfortunately there's not a definite job description for them so it makes it very hard when they come here, there's nothing — without having that definite job description, they're a little bit at lost ends, and they don't really know what they're really supposed to be doing.

The greatest area of confusion is whether they are to be employed in a social support role or with clinical skills.

And I know we've tried [Aboriginal] health workers here but they've never had a job description and its working [is] very messy and are they clinical or are they social? And what support are they meant to be giving us? It does need to be addressed.

There is some comment from those involved in palliative care indicating that the health system is more favourable to Indigenous people being employed as liaison officers or interpreters rather than clinical workers.

The health system is more focused on the liaison officer and the interpreters than they are on the health workers in the hospital environment.

Some argue that an emphasis on clinical skill is not necessary and the most important aspect of the work for palliative care is a social liaison and support role.

I guess I'm probably going to upset a few people here but I think one of the worst things that's happened with health workers is that, through trying to view a health worker as a clinical professional, we've taken progress [in a direction] which I think was

the worst thing that ever happened to health workers. Because some of the best health workers I've worked with, clinically haven't been anywhere beyond just basic first aid knowledge, but have been a real liaison person within the community.

As an extension of that argument, it is noted that if the Indigenous person assumes a clinical role then their clinical persona can alienate them from the very Aboriginal community they seek to serve.

Whereas what seems to happen is, once you turn them into clinicians, I think there's a huge loss of that role [they were doing previously] and the community finds it just as hard to come to them for clinical as they do for anybody else.

With regard to end-of-life care, participants prioritised relationship and knowledge ownership issues as much more important than clinical skills. As the full findings on communication, which are published elsewhere indicate,<sup>20</sup> effective communication with Indigenous people in the health setting is all about giving “the right story” to the “right person”.

[I] certainly think the health worker role — particularly in the palliative care setting — should not be clinically focused. Really, you need the right person who's the right kin, who has the right understanding, who has the ownership of that knowledge, to be the person there. And to some extent maintain a distance from the clinical side of things.

### **Satisfaction with Indigenous health workers**

The strong evidence from participants in this palliative care research is that AHWs are appreciated for their valuable contribution to the organisations for which they work.

Our indigenous health workers ... if we didn't have them I just don't know what we would do. They are just brilliant.

The liaison officer's very good, she comes down and talks to the people when we need them.

We have one Aboriginal health worker that works in the renal unit and I call on her quite a lot to come and talk to people for me and [I] find her very good.

Yeah it does help having Aboriginal people working in the clinical area.

## Discussion

It is increasingly recognised that modern models of health service provision, predominantly based on the Anglo-Celtic world view, are often experienced as alien to Aboriginal communities.<sup>21,22</sup> Communication problems, cultural misunderstandings, socioeconomic disadvantage, and racial discrimination are known to be factors that alienate Indigenous people from mainstream health care services.<sup>23,24</sup> According to Blackwell,<sup>25</sup> Indigenous patients and their families are frightened of white medicine, as it is only used when someone is very sick and after traditional methods have been tried first. The present findings from palliative care research affirm this fact, with descriptions of the fear and discomfort Indigenous people experience in association with Western medicine. The fear is exacerbated by differing cultural ideas of knowledge ownership and transfer.

In addition to this, language can be a barrier for many Aboriginal people who speak little or no English. Weeramanthri<sup>26</sup> reports that in a 1991 census, 33% of Northern Territory Aboriginal people spoke English either not well, or not at all. At least 40 different languages are documented to exist in the Northern Territory; more than 70% of Aborigines speak a language other than English in the home and 25% of them claim to speak little or no English.<sup>2</sup> Many Aboriginal patients speak English only as a second language or they may speak "Aboriginal English" which has a different grammatical structure and range of meanings compared with standard English, thus leading to potential misunderstandings.<sup>23,27</sup>

In the face of such alienation, participants reported that Aboriginal people would prefer to be cared for by members of their own community. The advantage of AHWs during the distressing

and sensitive time of end-of-life care is that they are able to understand both the spoken and non-verbal language of their people, and they are able to negotiate the Indigenous knowledge system and cultural beliefs. As Bryce<sup>28</sup> documents, in order to foster effective communication and trust, it is critical to use strategies to overcome the considerable language and world view barriers. The employment of AHWs is an important step in overcoming such barriers and contributes to Indigenous empowerment.

O'Donoghue<sup>29</sup> points to the importance of empowering Indigenous individuals and communities, and asserts that as a matter of priority, Aboriginal participation needs to be at all levels of health service including policy, administration and practice. While getting more Indigenous people into the workforce to provide culturally appropriate care is acknowledged as critical, as yet progress in this regard has been slow.<sup>5</sup>

The findings make a clear and unambiguous statement about the lack of AHWs presently employed in relation to palliative care service provision. This situation is seen as serious and is accompanied by a call to government authorities to begin to address the issue. The call echoes the Australian Nursing Federation recommendations<sup>30</sup> that the Australian government explore a broad range of initiatives for better health outcomes for Aboriginal people, including establishing strategies to facilitate Indigenous people becoming a stronger part of the health work force.

In the findings, a myriad of employment issues associated with AHWs are explored, including the problems of staff turnover and the need for sustainability, the desirability of employing individuals from the local community, and the significance of providing culturally appropriate support and flexibility to AHWs employed in health services. Controversy over the confused and unclear job description for AHWs is aired, with strong arguments for prioritising a holistic, supportive and encouraging role over clinical duties. The concern is expressed that too much emphasis on biomedical clinical skills for AHWs may alienate them from the very communities

they seek to serve. The cross-cultural liaison work of AHWs is noted elsewhere as a significant aspect of their role.<sup>23</sup>

The findings concluded with statements of satisfaction, which gave testimony to the value and importance of AHWs in the health care system. The high level of satisfaction resonates with similar descriptions of the important work of Aboriginal workers throughout the literature<sup>2,22,31-33</sup> — for as Hays<sup>34</sup> suggests, perhaps the most important overall strategy for improving Aboriginal health care is to incorporate Indigenous workers as partners and role models. Recent evidence indicates that gains to Indigenous health status in North America, Canada and New Zealand have largely been attributed to the training and incorporation of Indigenous people to provide health care.<sup>5</sup> According to Ring (cited in Armstrong 2004)<sup>5</sup> this approach could be just as effective in Australia if there was the appropriate commitment to do so, but that this needs to be properly funded and administered.

## Recommendations

Future health policy and service delivery development should include a consideration of the following:

- The limited number of Aboriginal people presently employed to care for their own people during the palliative phase of illness is a serious concern.
- The evidence of satisfaction with the work of AHWs highlights the significance of the contribution they are able to make, with respect to resolving the many complex palliative care service delivery concerns affecting Indigenous people.
- The importance of engaging in service delivery dialogue to clarify the role of AHWs for palliative care service delivery, so that they can be employed most effectively.
- The significance of a flexible work environment for AHWs who have to cope with end-of-life situations that is culturally respectful and supportive.

## Conclusion

While highlighting the valuable role AHWs presently play in health care, the findings emphasise that the current lack of availability of such workers for palliative care service provision needs serious consideration. This issue deserves the full attention of health policy makers and service providers, for as one participant stated:

I've always supported employment of Aboriginal health workers and I think that's one of the most important staffing issues to consider.

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## Competing interests

The authors declare that they have no competing interests.

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