

# The “right story” to the “right person”: communication issues in end-of-life care for Indigenous people

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## Abstract

**Objectives:** To explore communication issues faced by health care workers and Indigenous patients and their families in a palliative care setting. Effective communication with Aborigines is especially important because Aboriginal beliefs of health and sickness are so different from Western views.

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

**Results:** Participants highlighted the struggle associated with effective communication when working in a cross-cultural setting at the interface of Indigenous and Western health care. The findings record the wisdom and insight from practitioners who have extensive experience dealing with communication difficulties.

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THE COMMUNICATION OF INFORMATION is critical to the process of Indigenous primary health care.<sup>1</sup> When caring for Aboriginal patients, health care

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## What is known about the topic?

Communication among people from different cultures around health care issues is often difficult.

## What does this study add?

This study provides the perspectives of Aboriginal people and health care workers on the important communication issues, including communicating difficult news, cultural shyness, information being taken literally, difficulty in understanding Western medical concepts, language barriers and talking to the right person.

## What are the implications for practice?

This paper highlights the importance of communicating the right story (full and culturally appropriate information, appropriately translated and with opportunity for feedback to ensure comprehension) to the right person (recognising the importance of relationship, family and community).

staff need to be aware of a myriad of cross-cultural issues. Although anecdotal evidence indicates that the quality of communication to Aborigines in the health care setting can be extremely varied, there seems to be very little research in this area. This article seeks to address the dearth of information in this area by presenting recent findings from Australian research that developed a model for Indigenous palliative care.

The research that has been undertaken on the topic has mostly focused on communication issues from the perspective of Western medical practitioners. One such study<sup>2</sup> outlines frustrations felt by medical practitioners at being unable to relate to Indigenous patients and when faced with patients who were reluctant to talk. Although these issues are indeed pertinent, so too are the communication challenges faced by an Aboriginal patient and his or her family.

This paper explores some communication issues faced by health care workers and Indigenous patients and their families in a health care

setting. Effective communication with Aborigines is especially important because Aboriginal beliefs of health and sickness are so different from Western views. Weeramanthri<sup>3</sup> and Maher<sup>4</sup> outline the belief systems, saying where Aborigines emphasise social and spiritual dysfunction as the cause of illness, Western perspectives look at scientific, physical explanations. The need for cultural understanding begins here. In addition to these fundamental differences in explaining causality of sickness, there is also an issue of language. Weeramanthri<sup>3</sup> reported from a 1991 census that 33% of Northern Territory Aboriginal people spoke English either not well or not at all. So chances of effective communication without an interpreter are compromised, even before cultural considerations.

Our findings indicated that when providing end-of-life care for Indigenous people, it is crucial for health care staff to get the “right story” to the “right people”. In traditional Aboriginal systems, some forms of knowledge are only available to certain people and a sign of seniority is access to this knowledge.<sup>1</sup> It is essential that health care staff observe these family hierarchies.

## The research

The aim of the 2-year research project, funded by the National Health and Medical Research Council (NHMRC), was 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>5</sup> in hard copy or to be downloaded from the Internet ([www.mcgrath-research.net.au](http://www.mcgrath-research.net.au)). The findings discussed in this article relate to the data which illustrate the communication dilemmas in Indigenous culture.

## Ethics clearance

This project was conducted in compliance with the 2003 NHMRC guidelines on ethical matters in Aboriginal and Torres Strait Islander Health Research,<sup>6</sup> and the 2000 Australian Institute of Aboriginal and Torres Strait Islander Studies guidelines for ethical research in Indigenous Studies.<sup>7</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 Ethics 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 participating in the project, and a guarantee of confidentiality for the individual and the community was assured.

## Participant group

An Aboriginal Health Worker was a participating member of the research team, and 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, 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 people.

The interviews were conducted in four geographical areas in the Northern Territory including East Arnhem Land (Maningrida, Millingimbi, Elcho Island, Nhulunbuy, Yirrkala, Angurugu), the Katherine Region (Borrooloola, Ngukurr, Katherine), Alice Springs and Darwin. As the 2004 Australian Bureau of Statistics<sup>8</sup> figures demonstrate (Box 1), the populations (with Indigenous populations in parentheses) in these areas are small and thus the 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 confi-

## I Demographics

Region	Total population (Aboriginal population)
<b>East Arnhem Land</b>	
Maningrida	1645 (1366)
Millingimbi	992 (918)
Elcho Island incorporated with Galuwinku	1463 (1346)
Nhulunbuy	3804 (275)
Yirrkala	648 (493)
Angurugu	822 (721)
<b>Katherine Region</b>	
Borrooloola	824 (494)
Ngukurr	933 (844)
Katherine	8610 (1568)
<b>Alice Springs</b>	26 229 (3474)
<b>Darwin</b>	68 516 (5957)

Source: Australian Bureau of Statistics 2004 census data.<sup>8</sup>

dentiality reasons, as individuals may easily be identified. There were a total of 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 Worker (AHW) refers to a worker in health care who is Aboriginal.

### Data collection

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>9</sup> It is important to note that all of the data collection was completed by a respected AHW 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 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>10</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>11</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>10,12-14</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>15</sup> For economy of presentation, the selected nodes have been organised under categories that, when juxtaposed, build an outline of the issues.<sup>16,17</sup>

Much of the data collection was completed in remote communities, and for some interviews an interpreter was used. Hence, many of the language texts are not necessarily couched in fluid English. To help readability and improve clarity of meaning, some of the texts have had words added in square brackets. However, even with these additions some of the texts remain awkward in expression. Also, because the participants often talk in the third person about Indigenous people (eg, talk about "their culture", "the things they do") the verbatim text can give the misleading impression, at times, that the examples given are

from a European talking about Aboriginal people. It was considered important to make only minimal changes to the texts for clarity, to stay true to the participant and so that the reader still has a sense of the original word.

There is no identifying information associated with any quote from participants. Strict confidentiality was promised to participants in this study because of the sensitive Indigenous cultural information given by participants and the small size of the communities from which data was collected where any information about a participant could potentially lead to identification.

## Findings

### **Cultural sensitivity and respect**

Cultural sensitivity and respect are the key issues in communication with Indigenous people. Aboriginal culture can bring a multiplicity of views on health and healing; participants indicated these views needed to be respected not questioned.

I don't think you should interfere with some of their cultural things they do. And I guess talking to them like humans rather than talking down to them because they don't understand this big issue.

There was evidence of the damaging sequelae of lack of respect in communication as the following text outlines:

Yes, yes cringing isn't it ... [nurses talking to Aboriginal patients]. I know nurses are notorious for talking badly to patients and it's just that whole thing of — you're in hospital under my care, you'll do what I say type of ...

A key to this problem is lack of empathy: "Mmm, or they just can't step into [Aboriginal] shoes can they?" The data emphasised the need for cultural respect, interpersonal communication skills, and encouraging empathy with the Indigenous perspective. An important aspect of demonstrating that respect through communication is to approach Indigenous people with humility and openness, as outlined in the following text:

"I always say: look who should I talk to? Do you want to talk to me about it? Do you want me to get the doctor? I don't push myself in there."

There can be communication problems even with patients with a command of English because of the different cultural understanding of health issues.

### **The right story to right people**

Participants emphasised the importance of providing full information to Indigenous people so that they are able to make considered decisions about their treatment. The process of giving the full information is referred to as telling the "right story":

[Aboriginal people] want "story" ... All that information makes a big difference.

As the following text demonstrates, it is important for the story to be communicated to the appropriate people in the extended family and to people in their community.

Aboriginal people like extended families ... Darwin, Roper River, Katherine, Alice Springs, same everywhere. Yeah right story ... to the right people in those families so everyone knows then what is happening with that person.

They want story here [in the community], family here ... story here, story here, so we can talk to *our* people ... doctor tell some of us.

The reason for this is that Indigenous people can feel frightened and intimidated when out of their community and this will impact on their communication.

Because [Aboriginal] people are very intimidated in town. [Aboriginal people] often say yes, yes, because they don't understand for a start or they think that's what the person wants to know and they don't really want to have it [treatment] and they're frightened of them [doctors].

It was also noted that it is important to allow the time and space for feed-back from Indigenous clients to check that they have understood the full facts of the right story.

And I've always found if you're communicating with them get them to chat back to you so that you know that what you've said to them is actually what they're interpreted it to be whereas some people don't have the time for that. [Interviewer: So they are not checking the story?] Yes.

### **Obstacles/solutions to communicating the right story**

There are many obstacles that interfere with the process of communicating the right story. Following is an outline of the obstacles accompanied by suggested solutions to ensure effective communication.

#### **Communicating difficult news**

The first obstacle is the difficulty of communicating the facts of serious illness to individuals who will find the information threatening and anxiety-evoking.

Hard for doctors and nurses as we have to tell people what is wrong with them — especially when the family does not want to hear if we tell the main person in the family.

It is acknowledged that while this is a generic concern in palliative care, the problem is exacerbated for Indigenous people because of language barriers and differing concepts about healing and disease.

We find it really hard at family meetings. Even with someone doing the interpreter work . . . to actually get across to family just what the stage of the illness is and what the outcome is going to be.

However, the strong message by participants is the importance of being honest and open, particularly about the transition from cure to palliation:

“You have to be very clear when explaining to the families so they have sort of a good understanding of it.”

#### **Cultural shyness**

The second issue was noted to be a specific Indigenous cultural feature. References were made to the fact that Aboriginal people were

naturally shy and were not likely to talk openly and assertively, as would be more the norm in Western culture. It was stated that, in most cases, for the Indigenous person to communicate openly it was necessary to have an interpreter or advocate talking for them. It was noted, however, that with sensitivity and cultural respect communication can be effective: “They might complain or air their concerns to a balanda (European) if the balanda understands what they are saying.”

#### **Information being taken literally**

Participants spoke of the problems associated with Indigenous people taking statements made by health professionals literally. The following is an example of how an Aboriginal person interpreted a transition to palliative care discussion from her doctor.

She was there with all the doctors, [she thought] the doctors told her — You have got to go back to your family, you got to see your family and you have got to pass away in 12 weeks time.

Another example came from an end-of-life discussion:

We had an incident recently. It was explained that this gentleman was going to die so the family took him home and painted him up and put him under a tree for 3 days because they thought he was going to die right there and then. So that whole communication thing.

Thus it is important in communicating with Indigenous people to be mindful that information given can be taken literally. For this reason, health professionals need to spend time and energy ensuring the family understands the ideas being communicated.

#### **Problems understanding Western medical concepts**

Throughout the data collection there were extensive discussions about the problems at the interface of traditional and Western medicines. The important point in relation to this discussion is

the notion that Western medical terminology can be a barrier to communication.

As the following participant notes, this problem is shared by all consumers of biomedicine, but is particularly difficult for many Indigenous people who may have a different understanding of health and healing.

I mean there are a lot of white people that don't understand that medical terminology so doctors should break that barrier; she should sit down and talk in simple terms, use simple words that you can understand yourself as an ALO (Aboriginal Liaison Officer), a health worker or whatever, and take the message to that family.

Biomedical "speak" is a particularly important concern in relation to the issue of relocation for specialist treatment. As the following text illustrates, it is essential when Indigenous people (many of whom have not previously left their homelands) are being referred to the metropolitan area for specialist treatment that care is taken in explaining the situation. The move to the major treating hospital can have a devastating negative impact on their quality of life, so it is essential they understand the issues.

The use of translators in hospital is extremely important. So often you get people presented in hospital with virtually a terminal illness but there is an option to have chemotherapy or radiotherapy and that may or may not involve going down to [name of major treating hospital]. And the benefits of that chemotherapy and radiotherapy might be very dubious medically so it may not offer much in terms of advantage in either quality or survival. And I think Aboriginal people get a short deal in that.

As the following text explains, the solution is to translate the technical biomedical ideas into simple terms and language, take the time to discuss these ideas fully and include the appropriate people in the extended family in these discussions.

You have to sit with people; you have to talk to them and not down to them. You have to be responsible as a treating doctor to make

sure that the families are comfortable in what you are saying and that they understand everything that you are saying.

As one participant summed up: "So getting the full story and getting all the options I think is very [important]."

### **Language barriers**

The language issues associated with this study are complex, as the participants included a myriad of language groups with individuals along the continuum from those who did not speak English to fluent Anglophones. The challenge associated with the different language groups is reflected in the following text.

Sometimes it is a little bit hard for me if they are not from our area because Katherine has about 32 different language groups here and it is really really hard sometimes.

The problems created by the language barrier are much worse for people with limited English from the homelands.

Different if it's a person who's right up there with English and can understand English very well, [if they have] spent a lot of time in the western world, they can understand it. But not for people back here (homelands).

Indeed, some of the older people do not speak any English:

But like a lot of old people really don't speak English well, if at all, and we — we just sort of muddle along, you know.

Differing notions inherent in language contribute to communication problems. Often concepts do not translate to the words of a different language. A further complication is that the difficulty in understanding is not just with translation of words but with interpretation. When isolated in a hospital situation away from the community, the language barrier causes distress that can translate into emotional or behavioural problems.

And the nurses don't understand [Aboriginal] language for a start and they're uncomfortable and stressed and then they might be

seen as being naughty or playing up or something when really they're just — you know, in a foreign confusing situation.

The strong recommendation is to make sure family members are around during talks so they can provide support and interpretation:

But I think they should have a person — like a family member — to interpret in with the doctor . . . [Do they have that all the time here or not?] Sometimes, sometimes . . .

Also of importance is the use of an interpreter for difficult end-of-life situations.

If there is a language problem then we should be able to get an interpreter to walk through different stages with us.

Unfortunately, obtaining an interpreter can be a difficult process.

And the interpreter service — we have a lot of trouble accessing them. It's the routine getting the permission to access them from the regional director. It is a very in-depth routine to try to get the interpreter service — it's not an expensive service for what we need and — but when I do need them the service is very good.

### **Talking to the right person**

There are strong Indigenous cultural beliefs and practices about relationships guiding communication that make it essential to talk to the right person. As the following participant states, the complexity of this situation can make communication difficult.

The person that they would talk to is a health worker from their own family. And that is where we get into problems at the clinic. In this town there are 30 groups of people. It is not a community, the government call it a community, we have a community council but it is 30 groups of people. And there isn't interaction. There's respect of each other — but there isn't communication.

For effective communication it is essential that health workers understand the network of relationships and know to whom it is appropriate to

give information. This applies to the use of interpreters as well. For Indigenous people, as compared with European, the family networks can be extensive, and thus, for some health workers, saying the right thing to the right people can be emotionally challenging.

Mostly European people haven't got much family around for a start. Whereas here we can have anywhere up to 30 people in a room and everyone trying to ask questions.

Consequently, the findings emphasised the importance of communicating with Indigenous people through the medium of family meetings, and, if needed, with an interpreter. Individuals from the extended family can also be called upon to help explain information. Indigenous people should be allowed to decide the attendance at the family meeting so the right people are there.

So yeah, family conferences and things like that I think are quite an important thing when they're still in hospital so they can ask all those questions but not with white doctors or the rest of it, they need to have an Aboriginal person speaking their language I think . . . (Interviewer: So interpreting the story for them in language?). Mmm, yeah, because even if they speak English a lot of misinterpretation of information . . .

## **Discussion**

The cultural differences between the dominant Anglo-celtic group and Indigenous Australians are significant, especially in relation to death and dying.<sup>18</sup> The findings emphasise the challenges associated with cross-cultural communication during end-of-life health care. While affirming the prevalence of effective communication by health workers, the data also highlight the quite significant obstacles that have to be negotiated to ensure effective communication.

Cultural sensitivity and respect are the key issues in communicating with Indigenous people. This respect needs to acknowledge the different world view Indigenous peoples hold in relation to disease, health and healing. As Geth-

ing outlines,<sup>19</sup> current models of health service provision are mostly based on the majority Anglo-celtic world view which is often alien to Aboriginal communities and is also accompanied by an assumption of superiority to Aboriginal traditions of health and care.<sup>20</sup> Although there are differences in Aboriginal and Western health belief systems, Reid (cited in Weeramanthri 1997)<sup>3</sup> noted that Aborigines saw no

problem in reconciling their beliefs with acceptance of Western medical treatment. This is encouraging for health workers where effective communication could lead to productive treatment for the patient. The challenge for health care practitioners is to communicate effectively and deliver culturally appropriate care that nurtures the potential complementarity of traditional Aboriginal and Western beliefs.<sup>3</sup>

## 2 Factors affecting communication with Indigenous people in palliative care

### Facilitating factors

- Cultural sensitivity and respect
- Empathy
- Interpersonal skills
- Humility and openness to understand
- Talking to the “right person”
- Family meetings - involving extended family network
- Checking “story” is understood
- Patience and time in communicating “story”
- Honesty, particularly about transition to palliative care
- Use of interpreter and family advocate
- Providing all options, especially in relation to relocation for specialist treatment

### Effective end-of life cross-cultural communication The “right story” to the “right person(s)”

### Obstacles to communication

- Paternalism and patronising attitude
- Lack of empathy
- Context such as hospital can be threatening/disempowering
- Difficulty of communicating end-of-life information
- Language barriers
- Cultural shyness
- Information being taken literally
- Difficulties associated with Indigenous people understanding
- Western concepts of health care, especially medical terminology
- Not talking to right person
- Not including the extended family in discussions

Unfortunately, the findings revealed paternalism is still evident, as provided in the descriptions of patronising interactions between health workers and Indigenous patients. Collis-McAnespie and associates<sup>20</sup> argued that although there is now greater understanding and impressive goodwill in Aboriginal health than previously, outdated ideas and attitudes abound. The way forward is an emphasis on empathy, humility and openness to understanding the ways of different culture.

The central concept informing communication with Indigenous people was providing the right story to the right people. The notion of “right story” referred to the provision of complete information in language and terms that are fully understood by the Aboriginal patient and their family. Participants emphasised the importance of providing sufficient time and feedback to ensure that the Indigenous person has understood the fullness of the right story.

The health care setting can affect not only the understanding of the story but also the readiness of Aboriginal people to express their concerns. The example was provided of the intimidating nature of a hospital setting in this regard, where Indigenous people may provide consent to procedures because they are too frightened to disagree or express their concerns. This scenario was contrasted with the community setting where the Aboriginal person will feel more comfortable, and hence, more empowered. This is a particularly important point for end-of-life care for Indigenous people, in view of the fact that dying away from home is not desired by the patient, their extended family or community.<sup>21,22</sup>

In Indigenous culture, information needs to be effectively communicated to the right person(s) within the extended network of family. A thorough understanding of Aboriginal beliefs and practices in relation to the significance of relationship is essential to be able to understand who in the extended family network is able to receive information for a specific individual.

As outlined in Box 2, participants elaborated on six key obstacles to communicating the right story and provided detailed suggestions of strategies to overcome such problems. The difficulties associ-

ated with breaking bad news is a generic issue identified in the palliative care literature, not only for Anglo-celtic communities, but also for Indigenous peoples in other countries.<sup>23</sup> Cultural shyness, although shared by many other cultures, has specificity to Indigenous peoples. It is noted elsewhere that Indigenous people are intimidated by health care services that are not culturally appropriate.<sup>24</sup> The suggested solutions lie in advocacy, the use of interpreters and cultural respect and sensitivity. The issue of information being taken literally is an artefact created by the interface of two languages and two different world views. It can be ameliorated by careful explanation, the use of interpreters and checking and obtaining feedback on the understanding of the story provided. Weeramanthri and associates<sup>1</sup> argued that a significant aim of effective communication in Indigenous health is to demystify issues by breaking down the complex to more easily understood, simpler notions.

The fourth issue, problems in understanding Western medical concepts, is also shared by Western consumers of biomedicine where the complexity of medical terminology can be experienced as another language.<sup>25</sup> For Indigenous peoples, this fact is exacerbated by their differing understanding of notions of health and healing. Indeed, authors such as McMichael<sup>26</sup> would argue that there is a “profound cultural dissonance” between Aboriginal and non-Aboriginal beliefs of health and health care that needs to be addressed. The findings emphasise the importance of being wary of the use of biomedical language when dealing with the decision for an Indigenous person to relocate for specialist treatment. Past experience shows that such relocation can have disastrous consequences in terms of quality of life, and the decision is often taken without a reasonable understanding of implications on the part of the Indigenous person and their extended family. Ensuring individuals have the full story, by providing an interpreter as well as enough time and a full explanation, is essential. These findings resonate with the work of Collis-McAnespie and associates,<sup>20</sup> who also documented the stresses associated with relocation for specialist treatment.

The fifth issue is language barriers as a major obstacle to effective communication. At least 40 different languages are documented as being in use 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>18</sup> Many of the Indigenous people have lived on the homelands for all of their existence and do not speak English. The data indicate that there is a strong imperative to address the long-standing difficulties with accessing interpreter services.<sup>18,27</sup> The language barriers have a significant impact on the difficulty faced at the interface of Western medicine. Even for those who speak English there are complicating factors associated with understanding the concepts expressed. Carrol refers to this as the “significant semantic challenge”<sup>27</sup> and documents evidence of the difficulty for English-speaking Aboriginal health trainees in applying Western concepts of cause and treatment where they hold very different causal beliefs. Research in other countries indicates that Indigenous people tend to draw on their own beliefs to explain illness, even though they accept Western medicine.<sup>28</sup> Weeramanthri and associates<sup>1</sup> argue that effective communication is partly about negotiating between different forms of knowledge. Our findings point to the importance of health care workers being aware of the many potential cross-cultural obstacles to communication.

The final issue goes to the core of Indigenous cultural practice and highlights the importance of talking to the right person(s). For Aboriginal people, family networks are extensive and there are strong beliefs about with whom within the network it is appropriate to talk. Humility and patience in accessing the right person are essential aspects of effective work in this area. Because of the large numbers of people from the network of relationships that need to be involved in the care of the patient, family meetings are an essential medium for communication. In Aboriginal culture it is important to pay last respects before death even if this requires travelling long distances, so there may be many people from the extensive family networks with an interest in the patient.<sup>29</sup>

## Implications for practitioners

In summary, the findings indicate that health care practitioners should take the following factors into consideration in their work in Indigenous health, particularly during end-of-life care:

- Cultural sensitivity and respect;
- The importance of relationship to Indigenous people, which embraces the extended family within the context of community — this involves the core task of providing the right story to the right people by following relationship rules;
- An appreciation that Indigenous people can feel overwhelmed and threatened when away from their community and in a clinical setting;
- An understanding of the need for providing the time and space for feedback and dialogue on information given, with an appreciation that information can be taken literally;
- An appreciation of the challenges associated with language barriers, engaging an interpreter when necessary, and using simple terms;
- Acknowledgement of the different concepts associated with healing and disease;
- Provision of honest information;
- Communication with humility, by consulting with Indigenous people first and asking with whom it is appropriate to talk.

## Conclusion

Participants throughout the regional, rural and remote areas of the Northern Territory highlighted the struggle associated with effective communication when working in a cross-cultural setting at the interface of Indigenous and Western health care. This study records the wisdom and insight from practitioners who have extensive experience dealing with communication difficulties. Although mindful of the many problems associated with communication, participants were optimistic about solutions. As one participant summed up:

It is very difficult. But if people are prepared to just sit down and talk and work through things and come across the obstacles and look at how they can get around the obstacles,

then you achieve that sort of understanding, which is important in sort of very complex situations like death and dying issues.

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## Competing interests

None identified.

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