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TITLE

“Hiding the story’’: Aboriginal consumer concerns about communication related to chronic disease in one remote region of Australia.

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Running head: Hiding the story

“Hiding the story”: Aboriginal consumer concerns about communication related to chronic disease in one remote region of Australia.

Abstract

This paper reports on a collaborative qualitative study which explored education and communication practice related to chronic disease from the perspectives of Aboriginal people in a remote region of the Northern Territory where the prevalence of chronic disease is extremely high. Most Yolngu (Aboriginal people of Northeast Arnhem Land) do not speak English as their first language and few health staff share the language and cultural background of their clients. Semi-structured interviews were conducted with Yolngu community members and health staff in their preferred language in small groups or individually, in an approach that was flexible and responsive to the concerns and priorities of Yolngu researchers and participants. As well, health education interactions were videotaped to facilitate more in-depth understanding of the strengths and challenges in communication. An iterative and collaborative process of analysis, interpretation and verification revealed that communication and education related to chronic disease is highly ineffective, restricting the extent to which Yolngu can make informed decisions in managing their health. Yolngu participants consistently stated that they wanted a detailed and direct explanation about causes and management of chronic disease from health staff and rarely believed this had been provided, sometimes assuming that information about their health is deliberately withheld. These serious limitations in communication and education have extensive negative consequences for individuals, their families and health services. These findings also have broader relevance to all areas of health care, including allied health services, which share similar challenges in achieving effective communication. Without addressing the profound

and pervasive inadequacies in communication, other interventions designed to close the gap in Indigenous health are unlikely to succeed.

Introduction

Effective communication is crucial to ensure the quality and safety of health care. The challenge to achieving effective communication, however, increases with the extent of cultural and linguistic difference between service providers and users. In the Northern Territory 70% of Aboriginal peoples, who comprise approximately 30% of the population, speak a language other than English at home - and the cultural distance between health service providers and Aboriginal clients is often extreme (e.g., Maher, 1999; McConnel, 2003; Trudgen, 2000). The risk of miscommunication is also significant even for Aboriginal clients fluent in English when staff do not share the same cultural background and knowledge (e.g., Binang Goonj, 2006; Lowell et al., 2005; Trudgen, 2000).

Miscommunication between health care providers and Aboriginal patients has been identified as a major barrier to effective health care over many years and in a range of different health care contexts (e.g., Amery, 1999; Brennan, 1979; Campbell, 1995; Devitt & McMasters, 1998; Edis, 1998; Hill, 1994; Humphery, Weeramanthri & Fitz, 2001; Kemp, 2001; Lowell, 2001; Lowell et al. 2005; Shahid, Finn & Thompson 2009; Shannon, 1994; Trudgen, 2000). More than a decade ago a study of the social and cultural dimensions of end-stage renal disease among Aboriginal people in Central Australia described health communication as “seriously fragmented and deficient” (Devitt & McMasters, 1998, p. 164) and identified a lack of awareness and an acceptance of “a grossly deficient cross-cultural communication standard as the norm” amongst both health care professionals and their clients (Devitt & McMasters, 1998, p. 147). Similarly, a study of renal care for patients from Northeast Arnhem Land found that shared understanding of key concepts was rarely achieved between

staff and Yolngu patients, thus limiting the opportunity for patients to make genuinely informed choices in managing their renal disease and compromising the quality of care (Lowell et al., 2005). More recently a study of cancer care in Western Australia found that similar limitations in communication continue to restricted the opportunity for Aboriginal patients to participate fully in treatment and substantially compromised the quality and outcomes of care (Shahid et al., 2009).

The prevalence of chronic conditions is considerably higher in remote communities in the Northern Territory than any other population in Australia. In 2005 40% of the population were found to have at least two chronic conditions while amongst those aged 50 years, more than 60% had at least two conditions and 30% had at least three chronic conditions (Department of Health and Families, 2009). The NT Department of Health and Families recently released a strategic framework which acknowledges that “never before has there been a greater need to empower individuals and the community through an understanding of what causes ill health and what can prevent it” (Department of Health and Families, 2009, p. 1). Finding the best way to facilitate this understanding requires active engagement of Aboriginal people in a collaborative process to identify the limitations in current practice as well as strategies for improvement in communication related to chronic disease. This was the central aim of our project and this paper reports specifically on the experiences and concerns expressed by Yolngu about current chronic-disease related communication and education practice.

Study design

This exploratory study utilised an approach that has evolved over a number of years through previous work conducted in this region by members of the research team. The approach

draws on emergent and participatory methodologies including grounded theory and constructivist inquiry, utilising qualitative methods in a flexible process that is responsive to the concerns and priorities of Yolngu participants and congruent with Yolngu cultural protocols. An experienced Yolngu researcher (EM) coordinated the research in the community. The research team also included experienced Yolngu health workers (SY, ER) to support the coordinator and facilitate engagement with the local health services. The Balanda (non-Aboriginal) researchers each have different professional backgrounds and ranges of experience in Indigenous health. The first author (AL) was trained as a speech-language pathologist and has worked in the region in which this study was conducted, as both a researcher and service provider, over more than twenty years. She has participated in a number of collaborative projects concerned with communication between Yolngu and Balanda. RW has over thirty years of experience of working as both a nurse and educator with Indigenous people throughout Australia, mostly in remote NT. She has particular interest and experience related to cultural safety and chronic disease education for practitioners working in Indigenous health. SD is a Registered Nurse and academic who has worked in a range of health care settings including among the First Nations people of Far North Canada and Australia's Indigenous people.

Setting

The project was conducted in a remote community and surrounding homelands in Northeast Arnhem Land, Australia. The community was first established as a Methodist mission in the 1940s. Subsequent rapid cultural change has had a profound effect on all aspects of life for Yolngu in the region. However, local Aboriginal languages continue to predominate in communication among Yolngu, and traditional systems of social organisation, and cultural practices such as ceremonies, and hunting and gathering traditional foods, continue to be

important in the lives of most Yolngu. Most Yolngu do not speak English as a first language but all are fluent in at least one, and often several, Aboriginal languages. Oral English competence ranges from high to minimal and literacy in any language is often limited in this predominantly oral culture (Northern Territory Government Department of Education and Training [DET], 2010). There are two local health services: one provides primary health care to the main community and the other provides health care to the surrounding homelands. Yolngu are employed as health workers and community educators but none of the nursing, medical or allied health staff providing services in this region share the language or cultural background of their Yolngu clients. The turnover of Balanda health staff in the region is high, with a substantial proportion working on short-term contracts (Garnett et al., 2008).

Participants

The primary focus of this project was to explore the issues related to communication and education in chronic disease from the perspective of Yolngu themselves. Interviews were conducted with Yolngu health staff, clients and other interested community members (n=33). Non-Yolngu health staff (n=8) with extensive relevant experience were interviewed to provide contextual information related to service provision with this population. As well, six interactions between clients and health staff, which primarily focused on client education, were videotaped and participants were interviewed about the interaction.

Yolngu participants were identified through a range of strategies and 25 women and 8 men were interviewed, some on more than one occasion. Yolngu staff working with the local health services were invited to participate in interviews and in evaluation of education interventions. Community members were purposefully selected by the Yolngu researchers to include a range of ages (with the majority between 40 and 65) and a range of chronic conditions including diabetes, chronic kidney disease, cardiovascular disease, chronic airways disease, cancer and mental illness. All Yolngu participants had one or more chronic

conditions and/or close family members with chronic disease. Yolngu involved in the initial interviews, as well as other community members and health staff, also participated in the verification and feedback discussions that further informed the findings of this project.

Data collection and analysis

Culturally appropriate methods led by Yolngu members of the research team were employed to collect data. Semi-structured interviews with Yolngu community members and health staff explored the participants' experiences with communication and education related to chronic disease, their understanding of chronic disease and management and their ideas for improving communication and education for Yolngu in the future. Additional interviews were also conducted to obtain feedback on a range of educational resources. Interviews were recorded on audio or videotape. As well, six educational interventions were videotaped and participants interviewed to explore the effectiveness of communication in each interaction. An audit of resources related to chronic disease available in each of the local health services was also conducted and information was recorded related to format, language and content of each resource.

All participants were given the opportunity to use their preferred language, which for almost all Yolngu participants was one of the Yolngu languages. This was crucial to provide a genuine opportunity for Yolngu to express the depth and complexity of their ideas and concerns. Yolngu researchers and interpreters collaborated with the Balanda researcher to transcribe and translate the interviews into English, engaging in extensive discussion about emerging key themes. Oral feedback and verification sessions were subsequently held to share, confirm and expand on the emerging findings with interested Yolngu community members and health staff. A qualitative data management program (QSR International's NVivo 8) was used to code all transcripts. These codes were derived primarily from the data to avoid filtering the data through a pre-determined and restricted set of codes. The data was

further organised into categories, and repeatedly reviewed, in response to the themes emerging from the iterative and collaborative process of analysis and interpretation that continued throughout the project.

Findings and discussion

Three key and interrelated themes emerged from the interviews:

- the need for greater access to meaningful information to enable Yolngu to make informed decisions related to chronic disease prevention as well as management
- the limited extent of shared understanding of specific chronic diseases, their causes, consequences and management;
- a belief by some Yolngu that key information about their sickness is deliberately withheld from clients and their families.

Greater community access to information

Yolngu health staff as well as members of the wider community repeatedly emphasized the importance of Balanda health staff sharing the “deep, true and straight” story with Yolngu staff, clients and families:

The most important (thing is) for Yolngu to get the full story about the causes of the sicknesses, and for the family (senior Yolngu community member)

A Yolngu woman who lives in a remote homeland and has a particular interest in the area of health communication provided a vivid metaphor that captures the key concerns expressed by many other participants:

We are not getting effective education.... See the leaf on this tree? ... We get the information, it's like a bit of the leaf from the tree and then it disappears. It really doesn't sink in.... See that root of the tree? ...that's where the story lies, that's where the true story for us has to come from.

Yolngu working within health services also expressed concern about the extent to which information is shared between Balanda and Yolngu staff. A community educator explained: "...most often...Balanda health workers don't give enough health information to the Yolngu health workers." She then held up a pen to more clearly illustrate her concern:

This is a pen - Balanda only give the Yolngu the lid of it and not the whole pen. We need the full information...information on how to prevent and how to cure.... We as a community would like these types of information to be released and taught to us so that we can help our Yolngu people. (Yolngu health educator)

The participants in this project expressed a strong and urgent need for access to information from the Western medical domain to enable them to make genuinely informed decisions in managing their health. Assumptions that Yolngu do not need or cannot understand detailed explanations about chronic disease are strongly challenged by the Yolngu participants in this study. This is consistent with the findings of other research with Aboriginal people, for example, a study conducted with Aboriginal renal patients in the Northern Territory and four states reported that participants "felt strongly that they were inadequately informed, were frustrated, and wanted more information" (Anderson et al., 2008, p. 500) while a study of cancer patients and families in Western Australia identified the need for more information presented in a culturally appropriate and respectful manner (Shahid et al., 2009).

Sharing information with families was also considered important - and inadequate. For example, a Yolngu health educator was concerned when she realized how many people have

serious health problems which require medication, and claimed that patients and families do not receive adequate and timely information:

These patients need to know why they are on these medications. Some patients don't tell their relatives about these things. *They only find out when they really get sick.*

Then the doctors give information about the disease and explain to the family. The patients need nurturing from their communities, health clinics and family. (emphasis added) (Yolngu health educator)

One important barrier to community access to health information repeatedly identified by participants was language. None of the Yolngu participating in this project: researchers, health staff or community members, speak English as a first language. Most speak a number of Yolngu languages and their level of fluency in conversational English ranges from high to minimal. Even when Balanda health staff have some knowledge of local languages, Yolngu participants suggested that it is more effective for Balanda staff to use clear English (e.g., avoiding medical terms), rather than attempting to mix languages. Experienced Balanda health staff recognise their limitations in achieving effective communication:

So you have to have a strong [explanation] in language. Because I can talk until I'm blue in the face and I know just the way I am perhaps putting what I'm trying to get across, there's no way I can do it as well as somebody who is a Yolngu person who can interpret in a way that's relevant for their community. (Balanda health service provider)

Although Yolngu health workers are sometimes involved in consultations with the Balanda staff few are trained in interpreting and few Balanda staff are trained to work effectively with interpreters so the full potential for ensuring effective communication is unlikely to be realised. As well, many interactions occur away from the community in hospitals where

there are no Yolngu health staff. An Aboriginal Interpreter Service was established in the Northern Territory more than ten years ago and is available at no cost to Government health services. However, our findings indicate that it is still not common practice for health staff to engage interpreters. In common with previous research findings, (Amery, 1999; Lowell et al., 2005) few of the Yolngu participants in this project reported any involvement of a trained interpreter in their interactions with health staff, even in situations requiring informed consent such as surgery: two of the renal patients participating in this project described their distress when they were sent to hospital without knowing they were to undergo surgery or what the surgery was for.

English also predominates in communication related to chronic disease outside the clinical encounter. Our audit of educational resources available in the community found that the majority use written English (Lowell et al., 2010). As a result, many clients have limited access to information provided by these resources because they are dependent on someone else to read and interpret the content. Production of resources using oral Yolngu Matha and the recent implementation of a community health education program which employs Yolngu as educators have increased the potential for Yolngu to access to information in their own languages. Despite these recent improvements, the range of resources in local languages is still limited and utilisation of existing resources is far from optimal. Even when resources such as DVDs in local languages are available in the local health centre, staff are often not aware that they exist or do not have access to the equipment to view them.

Shared understanding of causes, management and consequences of chronic conditions

Language is not the only aspect of communication that influences the process of sharing information. Information presented by health staff in clinical interactions, as well as the

information presented in educational resources assumes a shared understanding of basic anatomy and physiology, as well as many other culturally specific concepts.

Most Yolngu have considerable anatomical knowledge as hunting for food such as wallaby and turtle is still common in this region. Shared understandings about how the human body works, however, are very limited. For example, Yolngu understand the function of the heart as the key organ in maintaining life but also to be primarily concerned with breathing - and lungs have no known function. The Balanda story of the role of the heart in pumping blood, the process of circulation and the function of blood are not part of Yolngu cultural knowledge:

Q. What does the blood do in the body? Do you know?

A. No, we don't know.

Q. What is the role of the heart?

A. It helps for the breathing, I don't know the health side much.

Q. What about the lungs - what is their role?

A. We don't know - only the smokers know that

(community members including experienced interpreter)

Similarly a young woman, who has relatively high fluency in English and considerable Western cultural knowledge was unclear about the function of the heart but thought that "it helps us to breath and helps the brain..." She was also very unsure about the function of the lungs but tentatively suggested that they "help the blood to move around – pump the blood around". The strong association between the heart and breathing and the absence of an association between the lungs and breathing within the Yolngu domain was repeatedly verified with many Yolngu.

A shared understanding of broad concepts such as respiration and circulation is assumed by health professionals in more specific communication related to, for example, the potential consequences of high blood pressure or smoking. Just as some shared understanding of the circulatory system is essential for any explanation about blood pressure to be meaningful, a shared understanding of the function of the lungs as well as circulation is also crucial for education about smoking to make sense. Even if Yolngu are aware that smoking has harmful effects on the lungs this knowledge is unlikely to have a strong impact when lungs are not perceived to have an important function in maintaining life.

Many participants expressed a strong desire to understand more about their chronic disease but even for those who had access to some information there was still considerable confusion about the term chronic disease itself as well as specific chronic conditions. The term *chronic disease* is now increasingly used within the community as well as the health service domain and the Yolngu research co-ordinator discussed the term with many of the participants, including Yolngu working in health services. She concluded that, “Really Yolngu don’t know the meaning of chronic disease... because the doctor is using that language, it’s a foreign language.” A senior health worker stressed that: “Chronic disease ... needs to be explained so that people can get the real meaning of it.”

The following examples from an interview with a Yolngu woman who has a relatively high level of fluency in English and extensive experience with health services illustrate ongoing confusion:

Diabetes makes you feel really tired and the two cells are not working properly. One of the cells helps you and I think mine was weak because I was consuming sugar and building up the sugar in my body. (Yolngu dialysis patient)

Like other Yolngu with diabetes, she was also very interested in, but unclear about, the role

of the pancreas:

That's the first one that went wrong for me, is that the one that is attached to the lungs? I have heard the name in the ARDS (Aboriginal Resource and Development Service) radio but not sure where it is in the body.... It's good that they tell the story on the radio but I would prefer for someone to actually come and tell us the story personally. They should tell us by explaining to us and also showing us pictures (of) where the pancreas is in the body. (Yolngu dialysis patient)

A patient with chronic kidney disease (CKD), who is also relatively fluent in English and has had diabetes for a number of years, was still confused about the sickness that the term *diabetes* related to: "I'm not sure but I think it's the kidneys" (Yolngu renal patient).

An education session involving this patient and a renal educator was videotaped and analysis revealed that the Yolngu participant did not understand the differences, and connections between high sugar, diabetes, high blood pressure and kidney disease. Although he was familiar with each of the terms he did not understand their meaning, believing that diabetes was the name of early stage renal disease, and he repeatedly sought clarification from the educator. As well, the educator was not aware of the extent or nature of his confusion.

Such serious limitations in the effectiveness of communication in Aboriginal health care have been repeatedly reported in the literature for decades (e.g., Amery, 1999; Anderson et al. 2008; Brennan, 1979; Campbell, 1995; Devitt & McMasters, 1998; Edis, 1998; Hill, 1994; Humphery et al., 2001; Kemp, 2001; Lowell et al. 2005; Shahid et al., 2009; Shannon, 1994; Trudgen, 2000). Not only do Aboriginal Australians struggle to access information essential to their health, indeed to their survival, but the health professionals with whom they strive to communicate often have only a very limited awareness of the extent to which meaningful communication is occurring. This story has been repeated in virtually every arena in which

Aboriginal Australians come into contact with mainstream services (see for example Lowell et al 2005; Shahid et al. 2009; Trudgen 2000; Wild & Anderson 2007) yet the evidence from this study suggests little improvement.

Not surprisingly, lack of shared understanding regarding underlying disease processes frequently resulted in lack of understanding of the purpose of interventions and a consequent failure to adhere to treatment regimes. This concern was confirmed by a Yolngu man with renal disease who expressed his frustration regarding his medications: “I have ten medications to take and I don’t know what they are....They should sit down and show you and explain it clearly.”

The need for on-going medication when there are no acute symptoms, as well as the benefit of taking medications that do not have the potential to cure the disease are also concepts that require clear explanation. The consequences when this understanding has not been achieved were described by a medical practitioner with extensive experience in remote health:

... often you see people who have the classic mix of Type 2 diabetes, coronary heart disease, chronic kidney disease and...they’re on a standard batch of medications. And I know that 50% of the time or more people don’t take those medicines because they might get a two-week supply and they might not clearly have that understanding of the long-term nature of the condition and the need to take those medicines. If they’re feeling better, why take them? (Balanda health professional)

Yolngu participants also repeatedly confirmed that inadequate information about medication is a reason why some Yolngu clients do not take their medication. One woman, who works in the health field but still felt she has not had adequate explanation about her medications, explained why understanding the reasons for treatment is important:

We take a lot of different medication for different reasons. Sometimes we just don't feel like taking all of them. I just take one and the rest I don't have. If we have the full information then we can see it as a clear picture and have a reason to take the medication and know why we taking the medication. (Yolngu health worker)

Effective communication about medications is also important so that the medication is not blamed for the sickness: “[T]hey do say this: ‘Stop giving me medication. This is why I’m getting sick’. They say this because they don’t have that information [about] why they are on that medication” (Yolngu community member). The distrust of Balanda medicine implicit in this comment was a recurring undercurrent in the Yolngu conversations during this project and has been reported in previous studies of Aboriginal clients and the mainstream health system (e.g., Anderson et al., 2008; Shahid et al., 2009).

The limitations and the consequences described in relation to communication about medication were also evident in communication related to other forms of management. For example, when instructions are given without explanation they were subsequently resisted and when treatment options were not clearly explained, they were rejected. A Yolngu woman who had been on dialysis for some years explained:

They were giving me advice but I was not taking it in, they told me to not have much sugar. I didn't understand the illness - I thought I would just be going to the local clinic only but this is where I am now (on dialysis)...during that time they never told any stories about this type of illness.... In 2005 I started getting fluid problems and swelling. They made an appointment for me to go to Darwin but I didn't go. Kidney is a silent killer - you cannot feel the pain. I did not know that I had that. I thought I was just diabetic. (Yolngu dialysis patient)

In another example, such lack of explanation about the underlying reasons for the advice given resulted in a serious deterioration in the health of one woman:

When I came back from Adelaide hospital I was told not to do any work. I thought I was alright so I start doing housework. I started working in the evening then I started vomiting. I even vomited a blood clot. I was rushed to the hospital. I thought I was alright but I was still sick, not alright inside my body. (Yolngu cardiac patient)

Just as advice given in a clinical interaction without clear explanation is resisted, community education that does not provide detailed explanations is not considered effective. For example, a senior Yolngu health worker described the limitations of the smoking education provided through a community health promotion activity that runs for a number of days each year:

One of the stories I heard during the healthy lifestyle week was there had not been enough information passed to the people. The full story was not coming out. Only the name 'cigarettes' was coming out, a lot about "smoking, stop smoking". The real meaning of it was not explained, the full story. What are the poisons that cigarettes contain and how many? How do our teeth and lungs get black? And also, explaining about craving for cigarettes – how do they make us feel this craving? Health staff should be here giving us the information...to tell us the story about the poisons from cigarettes in our body. They don't give the deep explanation. (Yolngu health worker)

In addition to the barriers imposed by information that is meaningless, untrustworthy or incomplete, the environmental barriers to acting on advice are often not understood by health staff. For example, health staff commonly give dietary advice; patients are told what they should eat but issues related to availability, affordability, and difficulties with food storage

and preparation are not addressed. A senior Balanda health professional suggests this reflects inadequate staff training:

They [health staff] don't get brief intervention training so they don't know how to talk to people for a start....people think that you need to give education about healthy behaviours for example. So you just tell people what the healthy behaviour is that they should be doing but you don't make any connection to what is available within their own setting ...and how they can actually bring that information and the reality together (senior Balanda health professional).

Humphery et al. (2001) described both the situation and the consequences of this pervasive communication failure. They identified the failure of the health system to provide accessible, acceptable and effective interventions for Aboriginal clients, stating that the health care system failed to take into account the requirements of Aboriginal clients or their capacity to follow prescribed treatment regimes. Further, the authors stated that the health care system then laid the blame for 'non-compliance' on the Indigenous clients, establishing a cycle of suspicion, blame and scepticism that was echoed in the findings of this study and previous research (e.g., Anderson et al., 2008; Shahid et al., 2009).

Hiding the story

The high prevalence of most chronic conditions in this region is relatively recent and some Yolngu strongly attributed these sicknesses to Balanda influence and cultural change. There was therefore an expectation that Balanda should share their full knowledge of the sicknesses that have resulted from the changes that have occurred subsequent to colonisation:

You the Balanda are the best person to talk to about these things. The way I see it the Yolngu are getting sicker and sicker because they are relying more on the Balanda way of life. (Yolngu health worker)

There was considerable distress that information about chronic disease was not shared early so the disease could be prevented or managed before it is too late. Concerns that so little funding was provided for prevention and early intervention while a large proportion of the funding was allocated to expensive tertiary care such as dialysis and surgery were commonly and strongly emphasised, particularly in feedback discussions.

As the study progressed it became increasingly evident that some Yolngu believe that health staff deliberately withhold information about their health. For example:

If she [clinic nurse] had the story she should have told me straight. I don't want [health staff] to hide the story from me. (Yolngu chronic disease patient)

And what we want now is that the doctors should give us the true information on such sicknesses...but they don't want to give out stories in full details. And I think that's why many Yolngu people are getting sicker all the time. (Yolngu health educator)

There was some speculation about why information about their health was not being shared with Yolngu:

Doctors sometimes do give us information but sometimes they hold back and not tell us. I think maybe they are scared to tell the Yolngu. (Yolngu chronic disease patient)

It was only in the final stages of the project, during the verification and feedback process, that more specific and disturbing ideas about a possible motivation emerged. During a discussion with a group of senior women the participants struggled to explain why Balanda would deliberately 'hide the stories' about these sicknesses and cautiously shared their suspicion that health staff would get more money if they allowed the sickness to get more serious. This

indicates a profound mistrust not only of the health system but also a lack of trust in the individuals working within the system, even though some of the women in this group have long-standing and close personal relationships with Balanda health staff. Contrary to widely held assumptions that information provided to Yolngu should be 'kept simple' the Yolngu participants in this project made it abundantly clear that they interpreted this approach as a deliberate strategy to allow their sickness to get worse. This concern was summarised by the Yolngu research co-ordinator in a direct appeal for action that she recorded on video to be provided as an attachment to the project report:

The Government, doctors or policy makers plant the disease in the first place because they do not give any help in the first place - they help the Yolngu when the sickness gets much bigger. They should try to help the Yolngu in the beginning so the sickness can be treated in the early stages. They only help in the middle stage or even at the end stages. They should also help the Yolngu by putting the money towards health promotions. So please try and stop planting the seed in the wrong stages. Put the money in the right place, the right stage. (Maypilama, Yolngu research coordinator)

Within Western society there is a general, although perhaps diminishing, trust in the medical system and advice and treatment are likely to be accepted even when the reasons are not fully understood (Hardie & Critchley, 2008). Such an implicit trust in medical advice was clearly not evident from the interviews with Yolngu in this project. Just as Yolngu interpreted ineffective communication to indicate a deliberate withholding of information, participants in the study by Anderson et al. (2008) also regarded "the lack of information as deliberate withholding" (Anderson et al., 2008, p. 501). In the absence of such trust, Yolngu clients wanted access to the relevant and detailed information from the biomedical domain that will allow *them* to make an informed decision about what action to take.

The term “rumbal watangu” (literally “the owner of the body”) was used by a number of participants when they explained that they were in charge of their own bodies and it was their decision how they took care of themselves. They wanted to make informed choices but did not want to be told what they should and shouldn’t do without explanation. The Yolngu participants argued that they need to have ‘the full story’ to make genuinely informed choices about how to manage their health. In a group that has so recently been colonized some degree of political resistance to Balanda attempts to control Yolngu behaviour is also a possible factor as previous research with this and other Aboriginal populations has suggested (e.g., Anderson et al., 2008; Devitt & McMasters, 1998; Harrington, Thomas, Currie & Bulkanhawuy, 2006; Lowell et al., 2005; McConnel, 2004; Shahid et al. 2009; Trudgen, 2000).

Although the Balanda health staff discussed the importance of relationship in establishing trust, it was evident from the interviews with Yolngu that, even with a positive personal relationship, trust can be compromised if communication is not effective and if the Yolngu feel that information is being withheld.

Consequences of ‘hiding the story’

Consequences of the perceived deliberate withholding of information included reciprocal deliberate withholding of information by the patient, refusal to attend or simply not showing up for scheduled appointments and resistance to taking medication. All the responses described as retaliation for health staff withholding information, were potentially or actually damaging to the clients’ health. The following example illustrates the profound impact ineffective communication can have on the effectiveness of chronic disease management:

An older woman with CKD had attended the regional renal clinic for review and was told that she would be contacted by phone with the results of her blood tests the following week. The renal clinic staff, however, did not contact her:

I waited and waited and nothing happened – maybe they are telling lies to sick Yolngu?

When she tried to obtain her results from her local clinic, the staff told her they did not have the results, making a joke about it which caused her even more frustration:

They've taken blood and I ask them the result and when I ask them 'where is my result?' they said 'nothing...maybe I put it in the rubbish' that's what they said! This is true...maybe they just want to play around with sick Yolngu, tricking, asking for injection (i.e. blood test)

As a direct response to this lack of feedback from previous reviews she refused to attend the next appointment unless she received the information that she'd been promised:

[The health worker] came and asked me if I could go to Gove again on the 15th and I said to [them] straight 'sorry...don't make a booking for me – an old lady like me might get a heart attack travelling all the time'. They have to come here, that's enough. If they give me information I can go...

Although she shared her concerns with the researchers, the Balanda health staff were not aware that she was distressed about their lack of communication until this was relayed to them at the client's request. She was then given the information about her test results and agreed to travel for her next review with the renal team.

Conclusion

The high prevalence of chronic conditions in the East Arnhem region of northern Australia profoundly affects the lives of Yolngu: the relocation of family members to a distant city for dialysis, premature death which is not understood and therefore results in blaming, conflict

and confusion, and the burden of caring for sick relatives on those who themselves often have chronic disease. The cultural, community and individual impact of this burden is exacerbated by ineffective communication between Balanda health professionals and the Yolngu clients, families, co-workers and community members.

Across all forms of information sharing the actual levels of consumer health literacy are rarely recognised or accommodated. Use of a foreign language, incorrect assumptions of shared cultural knowledge and different communication protocols all contributed to the serious failure of current approaches to education and communication related to chronic conditions. For Yolngu, the strong concept of individual autonomy and control, the individual as the “rumbal watangu”, contributed to a resistance to following directives unless the reasons for the suggested action are clearly explained.

The key priority for Yolngu - that health staff share their full story about the causes, nature, consequences, prevention and management of chronic disease - can only be achieved with effective communication. This is essential to enable Yolngu to integrate the biomedical explanations that they find relevant with their own knowledge related to health and illness and therefore exercise their control as the “rumbal watangu” in managing their health.

Yolngu are experiencing an epidemic of chronic disease, most of which is preventable. It is therefore imperative that action is implemented across all levels of health services to address the urgent need for improvements in communication and education as a key strategy in reducing this unacceptable burden of chronic disease that is devastating the lives of Yolngu.

The key criteria for ensuring effective communication related to chronic disease, identified by participants in this project, will be reported in detail elsewhere. In summary, these criteria include: access to detailed explanations in the primary languages of the target group; clear illustrations to support the oral explanations; competent Balanda and Yolngu working

together to ensure the credibility and accuracy of the information; and a process of information-sharing that is responsive to Yolngu needs.

The findings of this study can also inform communication practice in other areas of health care. In the context of speech-language pathology services, there is a particularly strong imperative to recognise and respond effectively to the communication needs of Indigenous clients and their families. This can only be achieved through a genuinely collaborative approach that recognises the importance of Indigenous expertise as a crucial component of effective service provision.

It is appropriate that the Yolngu should have the final word in this, their story:

We are all equal living on this earth, we are not animals. We all should help, listen and look after each other. (Maypilama, Yolngu research coordinator)

References

Amery, H. (1999). *They don't give us the full story Attitudes to hospitalisation amongst Yolngu people of North-East Arnhem Land: A comparative study*. Darwin: Aboriginal Resource and Development Service.

Anderson, K., Devitt, J., Cunningham, J., Preece, O., & Cass A. (2008). "All they said was my kidneys were dead": Indigenous Australian patients' understanding of their chronic kidney disease. *Medical Journal of Australia*, 189, 499–503.

Brennan, G. (1979). *The need for interpreting and translation services for Australian Aboriginals, with special reference to the Northern Territory: A research report*. Darwin: Department of Aboriginal Affairs.

Campbell, M. (1995). Communication with Aboriginal patients in the pre-hospital environment. *Australian Journal of Emergency Care*, 2(2),24-27.

Department of Health and Families, (2009). *Northern Territory Chronic Conditions Prevention and Management Strategy 2010-2020*, Darwin: Department of Health and Families.

Devitt, J., & McMasters, A. (1998). *Living on medicine : A cultural study of end-stage renal disease among Aboriginal people*. Alice Springs, NT: IAD Press

Eckerman, A-K., Dowd, T., Chong, E., Nixon, L., Gray, R., & Johnson, S. (2006) *Binang Goonj: Bridging cultures in Aboriginal health. 2nd ed.* Sydney: Elsevier

Edis, F. (1998). *Just scratching the surface: Miscommunication in Aboriginal health care.* (Unpublished Masters Thesis). Northern Territory University, Darwin

Garnett, S., Coe, K., Golebiowska, K, Walsh, H., Zander, K., Guthridge, S., Qin Li, S., & Malyon, R. (2008). *Attracting and keeping nursing professionals in an environment of chronic labour shortage: A study of mobility among nurses and midwives in the Northern Territory of Australia.* Darwin: Charles Darwin University Press.

Hardie, E.A. & Critchley, C.R. (2008). Public perceptions of Australia's doctors, hospitals and health care systems. *Medical Journal of Australia, 189*(4), 210-214.

Harrington, Z., Thomas, D.P., Currie, B. & Bulkanhawuy, J. (2006). Challenging perceptions of non-compliance with rheumatic fever prophylaxis in a remote Aboriginal community. *Medical Journal of Australia; 184*(10), 514-551.

Hill, P. (1994). Aboriginal culture and the doctor-patient relationship. *Australian Family Physician, 23*(1), 29-32.

Humphery, K., Weeramanthri, T., & Fitz, J. (2001). *Forgetting compliance: Aboriginal health and medical culture.* Darwin, Northern Territory University Press in conjunction with CRCATH.

Kemp, K. (2001). *Cross-cultural understanding and the Northern Territory Intensive Care Experience: Dismantling the wall. (Unpublished Masters Thesis)*. University of Sydney, Sydney.

Lowell, A. (2001) *Communication and cultural knowledge in Indigenous health care*. Darwin: Co-operative Research Centre for Aboriginal and Tropical Health.

Lowell, A., Brown, I., Marrjanyin, B., Flack, M., Christie, M., Snelling, P. & Cass, A. (2005). *Sharing the true stories: Improving communication between health staff and Aboriginal patients, Stage 1 Report*. Darwin: Cooperative Research Centre for Aboriginal and Tropical Health.

Lowell, A., Maypilama, E., Yikaniwuy S, Rrapa E, Williams R & Dunn S (2010) *Taking control of chronic disease: Strengthening communication and education strategies supporting self-management for Indigenous consumers*. Unpublished project report.

Maher, P. (1999). A review of 'traditional' Aboriginal health beliefs. *Australian Journal of Rural Health*, 7, 229-236.

McConnel, F. (2003). Compliance, culture and the health of Indigenous people. *Rural and Remote Health* 3 (online) 190. Retrieved from: <http://www.rrh.org.au>

Northern Territory Government Department of Education and Training (DET). (2010). *Annual Report 2009-10*. Darwin: Northern Territory Government. Retrieved from <http://www.det.nt.gov.au/about-us/publications/annual-report-200910>

Shahid, S., Finn, L.D. & Thompson, S.C. (2009). Barriers to participation of Aboriginal people in cancer care: Communication in the hospital setting. *Medical Journal of Australia*, 190(10), 574-579.

Shannon, B. (1994) Social and cultural differences affect medical treatment. *Australian Family Physician*, 23(1), 33-35.

Trudgen, R. (2000). *Why warriors lie down and die: Towards an understanding of why the Aboriginal people of Arnhem Land face the greatest crisis in health and education since European contact*. Darwin: Aboriginal Resource and Development Service.

Wild, R., & Anderson, P. (2007). *Ampe Akelyernemane Meke Mekarle "Little Children are Sacred"*. Report of the Northern Territory Board of Inquiry into the Protection of Aboriginal Children from Sexual Abuse. Darwin: Northern Territory Government.