Barriers to participation of Aboriginal people in cancer care: communication in the hospital setting

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Rates of mortality from cancer are markedly higher for Indigenous compared with non-Indigenous Australians,[1-4] even after adjustment for stage at diagnosis, cancer treatment and comorbidities.[5] Treatment disparity accounts for most of the survival deficit.[6]

Effective doctor–patient communication, particularly crucial in cancer care,[7] positively correlates with the development of a strong therapeutic bond, adherence to therapy, understanding of treatment risks, reduced patient anxiety, patient satisfaction and reduced risk of medical mishaps or malpractice claims.[8-10] Miscommunication can have adverse consequences, including misdiagnosis, procedures being carried out without informed consent, poor adherence to treatment and persistent health-damaging behaviours.[11]

Communication can be adversely affected by people's socioeconomic, historical and cultural backgrounds. Culture is a complex phenomenon encompassing knowledge, folklore, language, rules, rituals, habits, lifestyles, attitudes, beliefs and customs that link and give a common identity to a particular group of people at a specific point in time,[12] and doctor–patient communication can occur in a context where there is interplay between cultures. Concerns about communication between Indigenous patients and health professionals have been previously identified.[13-15] Physicians have been found to deliver less information and less supportive talk to patients of black and Hispanic background and of lower socioeconomic class, and to be less proficient in their clinical performance with such patients.[16] A study with Native Canadians identified history, trust and concept of time as influencing communication between them and physicians,[15] while physicians have documented the significant role of non-verbal communication in interaction with patients of native and First Nations (original inhabitants of Canada and their descendants) ethnicity.[17] If unaccustomed to these non-verbal signals, clinicians could easily misinterpret patient behaviour.

In Australia, few studies have looked at the extent, nature and consequences of (mis)communication between Aboriginal patients and service providers.[11,13] A 2002 study identified sources of miscommunication such as lack of patient control over language, timing, content and circumstances of interactions, differing modes of discourse, dominance of biomedical knowledge, cultural and linguistic distance, and lack of resources including trained interpreters.[13] In this research, we explored Aboriginal people's views and experiences of cancer-related services in WA and their impact on decisions about uptake of cancer treatment.

METHODS

Our study was approved by four Human Research Ethics Committees. An Aboriginal Reference Group established through invitation was consulted throughout the study period, providing input and feedback from and to Aboriginal stakeholders.

We conducted indepth interviews between 1 March 2006 and 30 September 2007 with urban and regional Aboriginal adult patients with cancer and family members who had been closely involved in the journey of the Aboriginal person with cancer or who had died from cancer. Purposive recruitment occurred through the networks of the researchers and reference group and through health professionals in primary or tertiary care to ensure inclusion of participants from different regions, sex and cancer types. Limited snowball recruitment (whereby existing participants recruit future participants from among their acquaintances) occurred in rural settings.
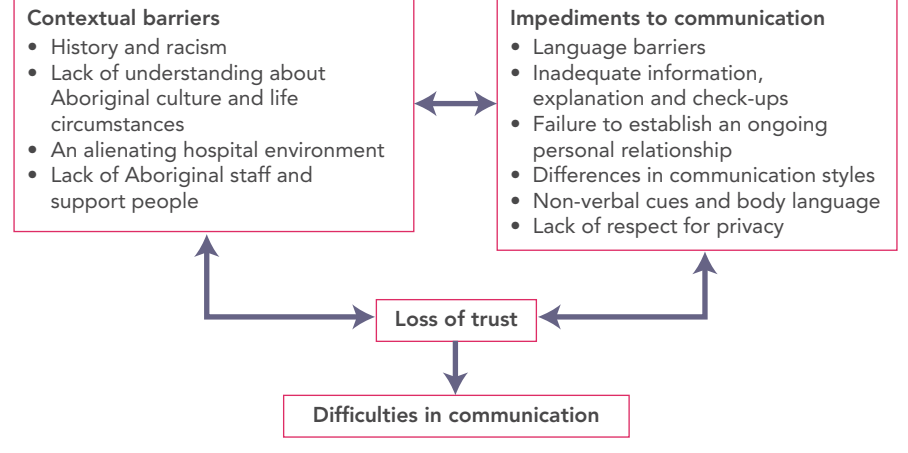
All participants spoke English and gave written informed consent. In semi-structured interviews, participants were asked to share the story of their journey with cancer or their journey with a family member with cancer, and to recommend ways of addressing any problems they faced. Difficulties encountered in accessing cancer treatment were explored.

ABSTRACT

Objective: To report Aboriginal patients' views about effective communication between Aboriginal people and health service providers in Western Australian hospital settings.

Design, setting and participants: Qualitative study involving indepth interviews between 1 March 2006 and 30 September 2007 with 30 Aboriginal people affected by cancer from across WA.

Main outcome measures: Aboriginal patients' views about the quality of communication within the hospitals, factors impairing communication and suggestions for improvement.

Results: Factors crucial to effective patient–provider communication such as language, shared understanding, knowledge and use of medical terminology require attention. Additionally, communication between Aboriginal people and health care professionals needs to be understood within a broader sociocultural and political context. Fear of the medical system and of being disempowered; mistrust; collective memories of the experience of colonisation and its aftermath; lack of understanding of Aboriginal customs, values, lifestyle and the importance of family and land; and experiences of racism were key issues impairing communication. Health service providers' inability to interpret non-verbal communication and the symbolism of hospital environments also posed problems.

Conclusion: Key areas for the attention of health service providers in communicating and caring for Aboriginal people in the hospital setting include culturally sensitive and empathetic personal contact, acknowledgement and respect for Aboriginal family structures, culture and life circumstances, an understanding of the significant role of non-verbal communication, and the importance of history, land and community. Employing more Aboriginal health workers in hospitals, and allowing Aboriginal people to participate at a decision-making level in hospitals is likely to improve Aboriginal people's access to cancer treatment, and would be important symbols of progress in this area.

1 Characteristics of the 30 Aboriginal patients and family members who participated in the study

Characteristic	Participants
Urban participants	11
Regional participants	19
Patients	14
Family members	16
Male	7
Female	23
Age group (years)	
30–39	4
40–49	18
50–59	5
≥ 60	3

2 Barriers to effective communication between Aboriginal patients and health service providers in the hospital setting

Contextual barriers
- History and racism
- Lack of understanding about Aboriginal culture and life circumstances
- An alienating hospital environment
- Lack of Aboriginal staff and support people

Impediments to communication
- Language barriers
- Inadequate information, explanation and check-ups
- Failure to establish an ongoing personal relationship
- Differences in communication styles
- Non-verbal cues and body language
- Lack of respect for privacy

Loss of trust

Difficulties in communication

In light of Aboriginal Australians' previous negative experiences with research,[18] relationship building was prioritised and interviews were conducted in a setting of the participants' choice. On rural visits, a respected appropriate local person nominated by the health service introduced the interviewer, and often remained throughout the interview.

Interviews were audio-recorded, transcribed verbatim and coded independently by two researchers. The interviewer maintained a reflective journal throughout. NVivo 7 (QSR International, Melbourne, Vic) software was used to assist data management and analysis. Participants' narratives were divided into broad categories to allow identification of key themes. Feedback sessions with available participants clarified whether emerging themes were an accurate reflection of participants' experiences. A social-ecological and holistic approach was considered for interpreting data.[19,20] Social-ecological epistemology considers the interrelatedness of several social elements[21] and looks at effects and relationships at multiple levels.[19,22] The holistic approach considers overall wellbeing in terms of physical, mental, emotional and spiritual aspects of healing and wellness.[20]

RESULTS

Thirty interviews were conducted with 14 Aboriginal patients with cancer and 16 family members. Demographic characteristics of the 30 interviewees are shown in Box 1.

Thematic analysis identified many concerns relating to hospital treatment. Communication issues with service providers were a salient concern, with subthemes of contextual barriers, impediments to communication and loss of trust (Box 2). These themes were often coded concurrently, highlighting the connection between them. These results align with the social-ecological model, highlighting the complex interplay between factors at different levels (individual, family, community, societal) and their impact on patient–provider communication. Although many of the issues identified are applicable to non-Aboriginal people when accessing treatment, their severity and impact on Aboriginal people is compounded by an aggregation of factors including their collective historical experience, cultural background and preferences, and poorer socioeconomic circumstances.

Contextual barriers

History and racism

> Racism doesn't help the process of getting better; it delays it. A lot of our people know. They don't have to hear it; they can see it in the person's actions.
> — *Urban female patient*

Underpinning all interactions, including health-related communication, between Aboriginal people and health care providers is a history of ongoing sociocultural and political isolation stemming from colonisation and its continuing, devastating impact on Aboriginal Australians and their culture. Consequently, some Aboriginal people choose not to consider treatment —

> Aboriginal women from remote communities make decisions not to come to Perth for treatment because of the way

they are treated here — *Urban female family member*

— or to delay their attendance. Racism and discrimination are frequently experienced by Aboriginal people in contemporary Australia.[23] Participants spoke about discomforting experiences with doctors' behaviour and feeling discriminated against (Box 3, A).

Peoples' views were shaped by both their personal experience and the collective recounted experiences of others.

> There were instances when Aboriginal people had to wait on the veranda, sit on the veranda outside the surgery while all the white people were seen to. Aboriginal people would sit there for a whole day and wait... Even if it was freezing cold... — *Urban female family member*

Lack of understanding about Aboriginal culture and life circumstances

Participants reported that many providers lacked understanding about Aboriginal culture, and the socioeconomic conditions and life circumstances of Aboriginal families. The importance of extended family and of country was often ignored in the hospital system. Some health professionals were seen as not wanting to deal with attending family members at all. Aboriginal patients' wishes to be at home for as much time as possible and to die in their country were underappreciated. Doctors had failed to inform some families that a relative had cancer or was gravely ill until days before death. A view reiterated was that terminally ill patients should be informed and offered the opportunity to return home as soon as

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3 Family members' responses illustrating contextual barriers to effective communication between Aboriginal patients and health service providers in hospitals

A. History and racism

"I just couldn't believe that these other doctors' surgeries wouldn't see him! They didn't say why they couldn't see him. Part of it was probably racism... They just didn't want to deal with Aboriginal people." — *Urban male family member*

"... when my sister was having her treatment, we would walk into the chemo unit, being the only three Aboriginal people there, you would have a lot of white people sitting around and they were just staring at you, like, and they don't come and sit next to you." — *Urban female family member*

B. Lack of understanding about Aboriginal culture and life circumstances

"... their understanding of Aboriginal culture, Aboriginal history, and just living circumstances is extraordinarily poor among hospital staff." — *Urban female family member*

"... the old lady was in the room and she didn't want to sleep on the bed, she wanted to sleep on the mattress, well, that was a bit hard for the Western world to understand, but that's all they knew is... sleeping on the floor on a mattress." — *Rural female family member*

"In the hospitals... you get where you can only have two people go in. If we were told like only two people... I can understand from the hospital's point of view when they keep the visitors or the communication things to a minimum, but it just sort of causes so many hassles, ... because then the families have to select only a couple of people, and then they have got to tell all of the other fellows... 'No', they can't." — *Urban female family member*

"He wanted to get back to the bush. He had spent all his life in the bush, and that last 7 weeks that we waited down there, he could have got up there". — *Rural female family member*

C. An alienating hospital environment and lack of Aboriginal support people

"... they come down and they feel isolated. They are out of their environment, lonely, and never been into a big hospital, so they feel isolated, scared and frightened." — *Urban female patient*

"When my dad was down there it was just like one big grey building. We were just about crying, and so was he. He wanted to get back to the bush." — *Rural female family member*

"I don't think they have got enough Aboriginal people there to work alongside the Aboriginal patients that they have." — *Urban female family member*

"There needs to be some sort of thing in place, there needs to be someone in the medical profession in the different areas that when one of these people are being sent down to Perth they need to be informed. They need to be able to keep in contact with the hospital, with the families, with everybody, even go down with them on the initial visit." — *Rural female family member* ◆

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possible (Box 3, B). Furthermore, suggestions by service providers about managing cancer, including taking liquid or "right diet" foods, and refrigeration of medications were sometimes unrealistic, confusing and frustrating.

Putting Aboriginal men and women together, mixing family groups inappropriately, male doctors attending female patients and vice versa, and young(er) providers advising older Aboriginal patients were also culturally inappropriate and problematic (Box 3, B).

An alienating hospital environment and lack of Aboriginal support people

Participants viewed the medical system as cold, indifferent, and inflexible. They felt their needs and preferences were not considered important within mainstream service provision (Box 3, C). Many commented on the need for Aboriginal support people to help patients and their families negotiate the hospital system, and to play a significant role in ensuring that patients understood treatment plans, possible outcomes and responsibilities. Just "having an Aboriginal face around" would help people settle better in the hospitals (Box 3, C).

Impediments to communication

Language barriers

English is not the language of choice for some Aboriginal people, particularly those from remote communities, yet there are no Aboriginal language interpreter services available in Perth tertiary hospitals. Family or community members may assist, but they may be stressed or lack adequate knowledge to provide informed support for the patient. Some Aboriginal patients lacked any support (Box 4, A).

Inadequate information, explanation and check-ups

Some participants had encountered medical staff who failed to explain treatment side effects and the purpose of medications, or who were not forthcoming about the sever-ity and prognosis of their illness. This angered patients and their families. Physicians' use of jargon and technical terms also caused frustration[24] (Box 4, B), as did perceived avoidance of talking with the patient.

For follow-up appointments, many Aboriginal people had often travelled hundreds of kilometres and waited hours for their check-up, and expected a thorough physical examination. However, some reported having a short 5-minute appointment, with the doctor looking at test results on a computer screen and showing little apparent concern for the patient.

Failure to establish an ongoing personal relationship

Staff turnover in hospitals affected continuity of care, impeded development of good doctor–patient relationships and quality of treatment and follow-up services, and disappointed patients. This contributed to patient uncertainty about engagement in treatment and follow-up. Patients felt that the way they were treated during hospital appointments reflected doctors' lack of real care for them (Box 4, C); this is an issue likely to have a particular impact on Aboriginal people because of the importance placed upon relationship within their culture.[25]

Different communication styles and non-verbal communication

Participants reported that Aboriginal people are "cluey", "intuitive", "can read minds", and have an ability to pick up whether a provider is genuinely interested in them as soon as they meet. Many physicians were felt to lack compassion or warmth in interpersonal interactions, whereas participants expected them to be "understanding", "compassionate", "concerned" and "empathetic" (Box 4, D). Many Aboriginal people are "reserved" during their visits to doctors, and are reluctant to admit difficulties with understanding (Box 4, D). This reticence could stem from believing that "the doctors know everything", lack of confidence to ask questions, silence as part of their culture or a learned behaviour from previous encounters within mainstream institutions. Such silence could be easily misinterpreted by health care providers.

Lack of respect for privacy

Shame and embarrassment about invasion of privacy was another reason why Aboriginal people felt uncomfortable communicating with medical professionals. Ward rounds and teaching sessions with medical students contributed to this discomfort:

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4 Interviewees' responses illustrating impediments to communication in hospitals

A. Language barriers

"There was another girl directly opposite him in exactly the same condition and she couldn't speak English. So, myself and another person there tried to tell them, 'Get someone down from her community. She needs to be able to communicate. She is in a world on her own. She needs to understand. Talk to her in her own lingo.' She couldn't understand the doctor; she couldn't understand anything. She was full blood. She needed someone from her community there." — *Rural female patient*

B. Inadequate information, explanation and check-ups

"…with the remote Aboriginals in the community…they go home and take this medication and they haven't got a clue what they are taking or what it is for or anything. If you don't understand why you have to do something, sometimes you don't do it." — *Rural female family member*

"If it was explained a little bit more… not so clinically — and that it's more visual — people can pick up a little bit more, but when it's not and you are just sitting across a table…" — *Urban female family member*

C. Failure to establish an ongoing personal relationship

"You come down here and you don't know the doctors. Each time you come down here it's a different doctor, and that really makes me angry because I have to repeat myself all the time… If I was to come here and see different doctors each time, they should read my notes before I come in, and not say to me, "Well, I haven't had time to read your notes. Could you fill me in?" I don't like that at all. It makes me very angry…" — *Rural female patient*

"They put out so many patients, they see so many patients, it is just like sheep going through the bloody drafting yard or whatever." — *Rural female patient*

D. Different communication styles and non-verbal communication

"…as long as they are good and they are friendly, because we are good judges of character. We can tell if someone likes us or is doing something because they just want to do it, or doing it because they care about what they are doing. We can pick that." — *Urban female family member*

"With a lot of Aboriginal people — and I know I have done this myself — if someone is talking to you and explaining to you and they are looking at you and nodding, 'yep, yep', but really it is over your head and you are too ashamed to say, 'No, I don't understand what you are saying', because you don't want to look dumb." — *Urban female family member*

E. Lack of respect for privacy

"…just having those 10 people all staring down at you like this, you know, that is intimidating enough in itself. So, I don't know that people would feel that comfortable with asking personal questions about their private life, their personal body parts." — *Urban female family member*

"A lot of Aboriginal women they don't like anybody touching them…doctor or anyone. Private parts or whatever; they get embarrassed." — *Rural male patient*   ◆

You wake up all you see these doctors there, all these white coats watching over you. I found that a bit embarrassing, and a bit annoying. — *Rural male patient* (Box 4, E).

Loss of trust

Issues of apparent medical failure occurred — for example, doctors underestimating symptoms and failing to recommend further diagnostic procedures when indicated by persisting symptoms. The wider failure of the system to deliver good care contributed to mistrust, miscommunication and poorer treatment outcomes.

Conspicuous distrust of hospital services was noticeable. This distrust stemmed from Aboriginal patients' negative encounters and experiences within the health system (Box 5). Trust develops as a result of broad-level social interaction, and requires reliability of the other within a given context. The absence of manifest respect for the culture of a particular group, together with repeated betrayal of trust, can create further distrust. Once distrust develops, all forms of involvement are undermined. People feel alienated from the system.[26]

DISCUSSION

Our study findings indicated that the tools needed to facilitate the entry of Aboriginal people into the medical system and to manage effective treatment are culturally sensitive and empathetic personal contact, acknowledgement and respect for Aboriginal family structures, culture and life circumstances, and the importance of land and community. Although Aboriginal peoples' experiences with cancer are not unique, they are overlaid by a collective experience of systemic racism within a public health care system.[27] There was considerable commonality in the reports of participants, irrespective of whether they were patients or family members, and despite variation in their demographic backgrounds.

Effective communication between patients and health care providers is essential for quality health care delivery,[16] and is inevitably affected by the culture(s) of those involved.[12] The dissimilarities between Aboriginal beliefs and cultural considerations and the approach of the Western medical system help explain Aboriginal people's underuse of health services.[28,29] Typically, health professionals focus on educating Aboriginal people to increase their biomedical understanding of disease processes. However, if health service providers are to be really effective as "healers", there are strong arguments for their making efforts to understand a patient's culture and social circumstances.

Sensitivity in patient care requires attention to the patient as a person, and this requires focus on patient–provider communication, understanding and relationship. Minorities around the world report less involvement in medical decisions, less partnership, and lower levels of satisfaction with their care providers.[15,16,30]

Limitations of our study include the under-representation of male participants. Possible reasons for this include: the main interviewer being female; women predominating as health care professionals and carers; there being a differential cancer survival according to sex; and higher use of health services by women.[31,32] The larger number of selected quotations from family members suggests that the family members were able to frame the experience of Aboriginal people better, and were more coherent and succinct in reporting.

The higher mortality rate from cancer among Aboriginal Australians reflects the fact that their cancer diagnoses tend to be made later, and their unwillingness to participate in mainstream cancer services. The focus for solving these problems must shift from considering Aboriginal people responsible ("why don't they come") to hospitals and staff accepting a responsibility for ensuring optimal care (including psychosocial care and cultural safety) for Aboriginal patients. The experience reported by Aboriginal participants shows that there is a need for attention at a systems level, and not at the level of the

5 Interviewees' responses illustrating loss of trust

"They would have known that, and that is the part that hurts the most, that we could have brought him back up here and looked after him and, yeah, spent that last 7 weeks with him. I feel that we were robbed of that." — *Rural female family member*

"I had three aunties go down there and die. So that sort of got to me, 'You are going down there to die.' They went down there good when you seen them off the plane and the next, what… 3 or 4 weeks after… they died. That's not a good sign for Aboriginal people." — *Rural female patient*   ◆

6 Suggestions and recommendations based on the study findings

At the hospital and system level

- Recruit Aboriginal people onto hospital decision-making committees
- Recruit Aboriginal support people and increase the number of Aboriginal staff in hospitals
- Make the hospital environment more welcoming to Aboriginal people
- Use interpreters or relevant support people to understand patients' concerns and needs
- Improve continuity of care by allowing more time to build rapport, and to know the person
- Provide care and follow-up closer to home where possible
- Increase linkages between the hospital and primary and community-based care
- Make available cultural safety training and encourage all staff, particularly doctors, to attend
- Improve communication skills in oncology staff through training in communication skills and Aboriginal cultural safety
- Rethink how patients are approached for consent around medical and other students

For health care professionals

- Mandate participation in cultural safety training so health staff understand and consider Aboriginal cultural needs (behaviours, preferences, importance of family, bond with the land, traditional practice)
- Understand and consider Aboriginal life circumstances such as rural or remote background, food, lifestyle, bond with the land, and the colonial past and its impact, and make realistic suggestions
- Show empathy, kindness and understanding for the person affected by cancer
- Use clear, plain language to communicate with Aboriginal patients and their families
- Explain options clearly and listen to patients' choices
- Make sure that Aboriginal patients and their families have understood what has been prescribed or recommended in regard to cancer treatment, follow-ups and management   ◆

individual patient–provider interaction, although the importance of both and the nexus between them is evident. Health care providers who do care have a vital role in creating system reform both inside and outside the hospital, so that the racism, the alienating environment, and the lack of culturally appropriate support, information and understanding reported in this study are addressed. Advocating for more Aboriginal health staff is an important part, and will help overcome current language and communication barriers.

Participants wanted an ongoing, trusting relationship with a provider who genuinely cared about them, but Aboriginal people often felt their wishes were not heeded and that their trust was betrayed. Good care must acknowledge that people care about relational issues such as being treated with dignity and respect and being heard.[33] Trust is crucial for patients in accepting difficult diagnoses, following complex treatment plans,[34] and for being satisfied with their medical care and having positive clinical outcomes.[35] The system appears to focus too much on clinical competence and too little on other psychosocial characteristics that encourage patient trust — equality, benevolence, integrity, respect, and honesty.[36] If treatment outcomes are to improve, the health system must become responsive to Aboriginal needs and heed their suggestions (Box 6). Participation and representation of Aboriginal people at a decision-making level in hospitals will help ensure these issues are addressed; such inclusion will, in itself, be an important symbol of progress. Increasing Aboriginal health literacy requires access to appropriate information and dedicated employment of Aboriginal staff.[24]

Much of this has been stated many times before, with little action or provision of resources to match the recommendations and promises. Inevitably, change has opportunity costs, but hospital resources need to be devoted to cultural safety in health care for Aboriginal people. While not challenging the value of randomised controlled trials of oncology treatments, improving (expensive) treatments for some should not be prioritised over the importance of reducing profound health disparities. Change also requires health service staff to undertake greater outreach to Aboriginal communities to build understanding and enhance relationships and support within communities.

Culturally appropriate, integrated and sustainable care for Aboriginal people with cancer requires a coordinated person-centred approach, involving patients, family members, Aboriginal health staff, and clinicians. Relationships developed through such networks are likely to help Aboriginal patients cope with the hospital settings, and ultimately enhance their confidence in communicating with the doctors. Many of the issues raised here are again identified in current national review processes, emphasising that the needs of Aboriginal people are indicative of the need for a broader health care reform process.[37]

COMPETING INTERESTS

None identified.

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