

## Health literacy in relation to cancer: addressing the silence about and absence of cancer discussion among Aboriginal people, communities and health services

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### What is known about this topic

- Aboriginal Australians have poorer cancer outcomes than non-Aboriginal Australians.
- Health literacy has been used widely to explore and account for disparities in health outcomes between groups.
- Differing understandings of cancer in some samples of Aboriginal Australians have been previously reported.

### What this paper adds

- Misunderstandings about cancer, including that Aboriginal people in this sample did not expect to experience cancer in their lifetimes, worked to silence discussion of cancer in Aboriginal communities, and act as barriers to screening, treatment and support.
- Promotion of cancer health literacy requires action at grass-roots community levels, as well as with Aboriginal health workers and health organisations and for speciality cancer services in working with Aboriginal people.
- The opportunities and barriers posed by the structure of the health system are also an important factor to address, specifically how workers in Aboriginal community-controlled health organisations can develop their own expertise about cancer and work in partnership with speciality cancer services.

### Abstract

Cancer outcomes for Aboriginal Australians are poorer when compared with cancer outcomes for non-Aboriginal Australians despite overall improvements in cancer outcomes. One concept used to examine inequities in health outcomes between groups is health literacy. Recent research and advocacy have pointed to the importance of increasing health literacy as it relates to cancer among Aboriginal people. This study examined individual, social and cultural aspects of health literacy relevant to cancer among Aboriginal patients, carers and their health workers in New South Wales. Qualitative interviews were conducted with 22 Aboriginal people who had been diagnosed with cancer, 18 people who were carers of Aboriginal people with cancer and 16 healthcare workers (eight Aboriginal and eight non-Aboriginal health workers). Awareness, knowledge and experience of cancer were largely absent from people's lives and experiences until they were diagnosed, illustrating the need for cancer awareness raising among Aboriginal people, communities and services. Some beliefs about cancer (particularly equating cancer to death) differed from mainstream Western biomedical views of the body and cancer and this served to silence discussion on cancer. As such, these beliefs can be used to inform communication and help illuminate how beliefs can shape responses to cancer. Participants proposed some practical strategies that could work to fill absences in knowledge and build on beliefs about cancer. These results were characterised by a silence about cancer, an absence of discussions of cancer and an acknowledgement of an already full health agenda for Aboriginal communities. To promote health literacy in relation to cancer would require a multi-layered programme of work involving grass-roots community education, workers and Board members of Aboriginal community-controlled health organisations and speciality cancer services, with a particular focus on programmes to bridge community-based primary care and tertiary level cancer services.

**Keywords:** Aborigine, Australia, cancer, diagnosis, health literacy, treatment

## Introduction

Recent evidence indicates that Aboriginal Australians have poorer cancer outcomes than non-Aboriginal Australians despite overall improvements in cancer outcomes (Supramaniam *et al.* 2006, Australian Institute of Health & Welfare 2011a). Engagement in cancer care for Aboriginal Australians is lower at all levels including screening, stage of cancer at treatment, continuity of care, compliance with treatment and 5-year survival rates (Cunningham *et al.* 2008).

One concept that has been used to examine inequities in health outcomes between groups is health literacy. Health literacy is a term generally used to describe an individual's ability to seek, understand and utilise health information (Jordan *et al.* 2010). There is a substantial body of literature that links low health literacy to a wide range of health-related deficits including less knowledge and understanding of their own health and treatment, lower self-management skills and proficiency in participating in preventive care and higher rates of morbidity and mortality from chronic diseases (Parker 2000, Dewalt *et al.* 2004, McCray 2005, Canadian Council on Learning 2007). People with limited health literacy have higher healthcare costs, higher rates of hospitalisation, engage in tertiary (therapeutic) healthcare services more frequently and engage in primary (preventive) healthcare services less frequently (Dewalt *et al.* 2004, Institute of Medicine 2004, McCray 2005). Health literacy and education play a fundamental role in the overall health of a society's population, potentially accounting for disparities within that population (Canadian Council on Learning 2007), and between mainstream and minority groups (Osborn *et al.* 2007).

Despite such strong and consistent findings regarding health outcomes, health literacy has been defined and conceptualised in different ways (Simonds 1974, Hohn 1997, Committee on Health Literacy for the Council on Scientific Affairs 1999, Nutbeam & Kickbusch 2000, Rudd 2002, Zarcadoolas *et al.* 2005, Nutbeam 2009, Sørensen *et al.* 2012). For example, the USA Institute of Medicine (2004) argued for health literacy to be seen as a shared function of social and individual factors noting the limitations of a dominant conceptualisation of health literacy as functions of an individual's knowledge or skill. Other authors encourage an even broader view of health literacy as encompassing activities that occur in the home, the workplace, the health system, the community and across the population, including cultural influences (Kickbusch 2002, Baker 2006, Nutbeam 2008). There is, however, only a minimal literature that specifically explores health literacy as relevant to

non-mainstream groups (Zanchetta & Poureslami 2006, Williams *et al.* 2007, Ishikawa *et al.* 2008, Shaw *et al.* 2009) and none that specifically examined health literacy in relation to Aboriginal people and cancer.

The structure and operations of the health system are one aspect of the broader conceptualisation of health literacy that has received little attention. Most research takes place within western medical systems that focus on the individual as the organising unit of healthcare and health system governance (Petersen & Lupton 1996, Petersen 1997, Clarke 2004). The structure and ethos of Aboriginal community-controlled health organisations (ACCHOs) are significantly different. ACCHOs are typically controlled by Boards comprising elected members of the community who have some influence over the priorities of the ACCHOs, operations. This self-determination is enshrined as a key element of Aboriginal community development and control in government strategy (Australian Government Department of Health & Ageing 2007). ACCHOs are mandated to provide primary healthcare, but specialist cancer treatment is not typically provided in these settings. Therefore, a study on cancer provides an opportunity to examine how community-controlled health services develop their own expertise in this relatively new area.

A recent review of advocacy and research needs in Aboriginal cancer care recommends that interventions to increase health literacy are needed (Garvey *et al.* 2011). It can be argued that any examination of health literacy for Aboriginal Australians must sit within the context of colonisation, dispossession, racism and collective historical trauma (Atkinson 2009, Taylor *et al.* 2010). These factors have led to Aboriginal people experiencing fear and mistrust of the medical system (Shahid *et al.* 2009b), along with an overall lower life expectancy of approximately 20 years compared with non-Aboriginal Australians (Australian Institute of Health & Welfare 2011a). Language differences (Simpson *et al.* 2011), barriers to information access (and corresponding lack of knowledge) (Shahid *et al.* 2009a) and considerable social and economic pressures can each (and in combination) (Wood *et al.* 2008) contribute to lowered health literacy for Aboriginal Australians in relation to cancer. In addition to these structural factors of exclusion, Aboriginal people may have differing views of health and illness that do not align with western biomedical models (McGrath *et al.* 2006a, Wood *et al.* 2008).

In Australia, research with mainstream populations has shown a relatively good understanding of cancer that has increased over time (Donovan *et al.*

2004). Some research studies with immigrant communities, such as those with Greek (Goldstein *et al.* 2002) and Chinese (Yeo *et al.* 2005) heritage, show gaps in knowledge and understanding of cancer. Previous studies have demonstrated the lower priority and differing understandings of cancer held by Aboriginal peoples. Interviews with Aboriginal patients, caregivers and health workers in the Northern Territory highlighted that cancer was perceived to be a lower priority, given the primacy of diabetes and end-stage respiratory disease for Aboriginal communities (McGrath *et al.* 2006b). Research and consultations conducted in Queensland and New South Wales (NSW) found that talking about cancer was discouraged as it might tempt fate (Prior 2009), highlighting a tendency to keep a cancer diagnosis private to protect individuals or their family (Simpson *et al.* 2011). Cancer has been perceived as a death sentence by some Aboriginal people (Prior 2009, Shahid *et al.* 2009a, Simpson *et al.* 2011), believed to be contagious (McGrath *et al.* 2006b, Shahid *et al.* 2009a), a form of pay-back or punishment for something they or their family has done in the past (McGrath *et al.* 2006a, Shahid *et al.* 2009a, Simpson *et al.* 2011) or a manifestation of bad spirits (Prior 2009). Specific types of cancer, such as cervical cancer, may acquire other meanings, such as being perceived as a 'dirty' disease (Prior 2009). Previous research has also highlighted the practical implications of familiarity with the mainstream health system, indicating families most likely to benefit from cancer services as those that had connections with the health system via their work and that this connection provided sufficient knowledge of the health system to effectively negotiate it (Shahid *et al.* 2011).

The aim of this paper was to understand and integrate the perspectives of Aboriginal people, their carers and health workers regarding the health literacy required for engaging with cancer screening, diagnosis, care and treatment. We considered health literacy in relation to cancer based on a previous definition:

'the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions'. (Ratzen & Parker 2000, p. vi)

However, we drew upon scholarship that positions health literacy in broader terms as a dynamic interaction of multiple individuals' skills and knowledge, social and cultural influences, mediated by colonial history and as experienced within two health systems (Aboriginal community-controlled and mainstream). Specifically, we examined participants' narra-

tives of their cancer experience in relation to health literacy as an individual capacity, as well as the social and cultural contexts that are important for Aboriginal people and communities in relation to cancer. We use these findings to suggest recommendations for practical programmes to support health literacy in relation to cancer and highlight the importance of the structure of the health system, particularly the interaction of ACCHOs and speciality cancer services situated in mainstream facilities.

## Method

This study was conducted in NSW as a specific project to examine the experience of cancer among Aboriginal people and is part of a larger project involving cancer clinicians and Aboriginal researchers as principal investigators, associate investigators or members of an advisory group. The Aboriginal researchers consulted with community members via visits to numerous communities across NSW regarding correct protocol for data collection.

This paper includes results from semi-structured, in-depth interviews conducted with three groups of people: (1) 22 Aboriginal people who had been diagnosed with cancer, (2) 18 people who were carers of Aboriginal people with cancer and (3) 16 healthcare workers (eight Aboriginal and eight non-Aboriginal health workers). Cancer patients, their carers and workers who work with Aboriginal people with cancer were recruited from Aboriginal Medical Services (AMSs), hospital oncology services, palliative care facilities and personal networks. Fliers advertising the study were placed in AMSs and were given to oncology staff at hospitals to hand out to potential participants with a toll-free telephone number to contact regarding participation. Additional recruitment occurred via referral from participants and existing community contacts of Aboriginal researchers. The Aboriginal Community Liaison Officer then spoke to potential participants, explained the study to them including the voluntary nature of participation and arranged an interview. Interviews were conducted between 2008 and 2011 at a location convenient to the participant and typically took between 1.5 and 2 hours. Informed consent was provided by all participants. The majority of the interviews with Aboriginal people with cancer and with their carers were conducted by trained Aboriginal interviewers (PJ, VS, CJ). It was not a requirement of this study that both patient and carer participate, hence these two data sets are not linked. Interviews with healthcare workers were conducted by experienced non-Aboriginal researchers. The research team met with the cultural

mentor (CJ) on a monthly basis to monitor the cultural safety of these ongoing processes. This project was approved by the human research ethics committees of the Aboriginal Health and Medical Research Council, The University of New South Wales, relevant committees of local health authorities and the Cancer Council New South Wales.

Participants were invited to talk about their personal and/or professional experiences with cancer including their understanding of cancer, their thoughts about the Aboriginal community and issues around cancer, their personal experience of cancer diagnosis and treatment or their experiences caring for or working with someone with cancer at diagnosis and during treatment. Participants were also asked to provide some of their history and demographic data. Participants were acknowledged for their time and effort (Davidson & Page 2012); patient and carer participants were provided \$60 for their time and healthcare workers were offered a \$30 gift voucher.

This study originally sought to recruit people who had experienced cancer in relation to specific roles – as either patient, carer or health worker. However, a number of participants had experience of more than one and sometimes all three roles. For this analysis, we have categorised each participant as one of patient, carer or health worker. Where their experience in other roles is important to their perspective, we have included this information. In this way, participants were able to reflect on, for example, what they had learnt as a health worker where it also related to their experience of living with cancer.

The interviews were digitally recorded and then transcribed. The cultural mentor/advisor (CJ) provided commentary and clarification on Aboriginal language and terms used including notes on emerging themes across interviews. Transcripts were also checked for other issues of accuracy and de-identified (removal of identifying information and application of pseudonyms). Interview data were managed using the computer software package NVivo 9 (QSR International, Doncaster, Victoria, Australia) and coded for six major themes. These codes were developed from the literature (relating to both Aboriginal and non-Aboriginal peoples' experience of cancer care) and through ongoing workshops with the Aboriginal research staff who had conducted interviews with patient and carer participants. Close reading of the three groups of data (patients, carers and health workers) was conducted by the lead author (CT).

To inform this analysis, we drew upon interpretive description (Thorne *et al.* 2004, Thorne 2008) in which researchers are urged to extend their gaze beyond generic qualitative description to that of inter-

pretive explanation addressing questions such as how are the phenomena similar or different, how do they relate to each other, what patterns exist and how do they operate. Thorne suggests that analysis in this way can illuminate complexities of experience into a coherence that can inform healthcare policy (2008). In particular, we wanted to ensure that our view of health literacy in relation to cancer was broad (not limited to individual or even social perspectives, but encompassing cultural and health service influences) and to employ the resources available to us (the personal and professional experiences of Aboriginal and non-Aboriginal researchers) to thoroughly interrogate the data. To achieve this, a draft of this paper was provided to the Aboriginal researchers (CJ, VS, PJ) for their comment in a series of workshop-style discussions where differing experiences of cancer (personal and interpretive) were examined. The paper was also reviewed by the ethics committee of the Aboriginal Health and Medical Research Council.

## Results

Twenty-two patient participants were interviewed including 16 women and six men. Three participants were born in the 1940s, nine in the 1950s, four in the 1960s, two in the 1970s and one in the 1980s. Age was not reported by three participants. Eight participants reported that they were working full-time or part-time, four participants reported receiving sickness benefits and another four reported that they were not working. Work status was not reported by six participants.

Eighteen carer participants were interviewed including 16 females. Fourteen carer participants identified themselves as Aboriginal Australians. Eight participants reported caring for a parent with cancer, five cared for their spouse or partner, two for their daughter, one for their sibling and two participants reported caring for more than one family member with cancer.

The health worker sample included five men and 11 women. Eight participants identified themselves as Aboriginal Australians. The participants worked across a range of settings and in diverse roles including 10 participants working in urban settings, two in coastal settings and four in rural settings. Professional roles included three oncologists, two educators, four liaison workers, two nursing specialists, one cancer co-ordinator, one dietician, one health service manager, one General Practitioner registrar and one men's health worker. In relation to experience and engagement with Aboriginal patients, 10 described their experience as limited and six described this as extensive.

The findings have been framed as opportunities to address health literacy in relation to cancer for Aboriginal communities. In this way, we hope to avoid framing results in terms of 'deficiency' or 'pathology' of Aboriginal people or communities (Kowal & Paradies 2010). We aim to acknowledge opportunities for building new knowledge and strategies to better the lives of Aboriginal people diagnosed with cancer, and their families. First, we describe cancer as a concept, which was largely absent from people's lives and experiences until they were diagnosed. This provides an opportunity to raise awareness of susceptibility to cancer among Aboriginal people, community and services. We next identify some beliefs about cancer that may differ from the mainstream western biomedical views of the body and cancer that may serve to silence discussion on cancer, and propose ways in which these beliefs can be used to shape responses to cancer. Finally, we propose some practical programmes and responses that could work to fill absences about cancer.

### Recognising susceptibility to cancer

Patient and carer participants described limited cancer knowledge, experience or expectation prior to the diagnosis that affected them. Nola (a carer) commented that she 'didn't really think that cancer would touch my life'. Tom (a carer) revealed that he did not know what an oncologist was until his daughter was given an appointment to see one. Nigella, a patient who had previously worked in the health sector described her own lack of experience with cancer as well as drawing a parallel with this in her work as a health educator:

Cancer has never sort of crossed my life till now ... I used to be a health worker, an educator, but cancer was never part of my life, I never knew anyone with cancer, I never seen anyone with cancer, maybe on TV but not in the here and now, cos I was always busy with Aboriginal health and teaching Aboriginal health, but cancer was never part of our programme, which was a shame. (Nigella)

Silence around cancer was reinforced by participants' comments on the representations of cancer in mass media. These comments centred on the absence of Aboriginal people in public campaigns, and hence the lack of meaning these campaigns held for participants. Pearl (a patient) described the absence of 'dark skin' and the inclusion of 'Asians... and white people and old people' as leaving her to feel as if she is not 'part of their plan'. Similarly, William (an Aboriginal health worker) recalled an advertisement for prostate cancer, but described it as 'mainstream' with 'a couple of white men' and no representation of Aboriginal people.

Some participants noted that cancer was 'new' for Aboriginal communities. This perception may be influenced by prior instances of death from cancer that were not noted as such or described as something else. In addition, all participant groups noted the large number of other health conditions that were of priority for Aboriginal communities, which further silenced discussions of cancer. While other issues are noted as important for Aboriginal health, Evelyn (Aboriginal health worker) strongly rejected the notion of 'competition' between diseases and urged careful presentation of a 'complex and dynamic situation where we have to care for people where they are' in line with Aboriginal culture where an emphasis is placed on holistic and integrated views of health.

### Recognising opportunities to learn from each other

Community understandings of cancer were described by each group of participants as low and as imbued with myths or misunderstandings. Equating a cancer diagnosis to a 'death sentence' was a strong theme in these data. Carina (a carer) described cancer as:

'a big silent word ... you mention cancer and God, everybody just caves in'.

The silence surrounding cancer was linked to its association with death:

...there's also some degree of lack of education among our people so .... you have some families who might abandon the person who has cancer because they are too frightened by it and they think that cancer is a death sentence, so as soon as the diagnosis comes, they shut down with fear. (Evelyn, Aboriginal health worker)

Fear of cancer was described as affecting numerous areas of the cancer prevention and care journey. For screening, fear of cancer was described as preventing effective communication about the meanings and use of screening tests. In the example below, Evelyn (an Aboriginal health worker) describes the difficulty in explaining cervical cancer screening in terms of detection of pre-cancerous cells:

And there's also that psychological barrier, that fear that ... if you get a problem with your test, it means you've got cancer. So there's room for education there in that this is a test looking for cells that could become cancer if you left them there.

Wesley (a patient) describes the reluctance of community members to undergo treatment, specifically surgical treatment, as it is believed to hasten death:

Wesley: But a lot of the old fellows they don't want to get operated on because they reckon that when they get cut open it spreads ... They are frightened.

Interviewer: Frightened of it spreading?

Wesley: Yeah. And a lot of them don't want to have treatment ... Because they reckon it will make you die quicker.

Given community perception of cancer equating death, support for people diagnosed with cancer can be affected by these concerns and fears. Desley (a patient) describes the relationship between support and fear, misunderstandings and general lack of knowledge about cancer. Desley's case is compounded by her diagnosis of a cancer that is not typically within public discussion:

Everyone talks about breast cancer and when cancer day comes, it's all about breast cancer, it's all about a pink ribbon or something else, but having this what I've got, being Aboriginal, being there with a disease that no one knows about and being on your own is really is a really bizarre thing, you know. (Desley)

Some patient and carer participants described changes in the way they viewed cancer. From initially understanding cancer to be a harbinger of death, participants reframed cancer as akin to chronic illness:

When I was first diagnosed with cancer, I thought it was a death sentence. I thought it was something that was going to kill me immediately. ... So, I look at it now as cancer is ... a chronic disease that is just something that can be managed ... rather than looking at it as a sickness or an illness that can't be manageable. So I look at it as something that I am living with, I am living with cancer not dying from it at the moment. (Desley)

### **Opportunities for practical services and programmes for health literacy in relation to cancer**

The majority of participants expressed a need for increased information to be provided to Aboriginal communities about this 'bloody disease'. Specifically, information was required that facilitated community members' awareness of cancer as well as its meanings, signs and symptoms, so that they were able to engage in testing and prepare for diagnosis and treatment:

I think probably just awareness, so being aware of what's involved, even before you get the bloody disease, so just having better knowledge of things, what's available, what's out there to be watchful for or fearful of and what you can do about it. (Max, patient)

Participants drew comparisons between education programmes on a range of other health issues that they knew of or had been involved in (as participant or educator), but typically stated that they knew of few, or no, such programmes for cancer. There was an expressed need for cancer education programmes

at a number of levels – for community members and for health workers:

There's no information session at the ground roots, on the reserves and that to speak to people ... I belong to the Aboriginal Women's [group] ... we had all these information sessions, but I don't think we had one on cancer. We done a lot of women's problems, but we didn't touch on cancer and I guess it didn't even come to mind anyway, what I can remember we didn't, you know, it wasn't talked about. (Nola, carer)

Similarly, Nichole (a non-Aboriginal health worker) draws a comparison between the resources provided for other health issues with the few (or none) provided for cancer for Aboriginal communities. In the quote below, Nichole identifies that her service could be doing more to promote cancer awareness:

It would be good to have more info, more widespread information about cancer. We've got so much health promotion brochures on 'What's Diabetes?' or 'What does Speed or Cocaine do to the Body?' you know all those kind of ... but there's nothing ... I don't think I've seen one thing on what cancer does to the body or what you can do, or what causes cancer, those kind of ... health promotion materials would be useful. (Nichole, non-Aboriginal healthcare worker)

### **Discussion**

In this qualitative study involving Aboriginal people diagnosed with cancer, their carers and health workers, a number of findings emerged in relation to health literacy as relevant to cancer. Misunderstandings, centred on equating cancer with death, worked to silence discussion of cancer in Aboriginal communities, and act as barriers to screening, treatment and support. Strategies to redress these misunderstandings and promote health literacy in relation to cancer rested with grass-roots education campaigns within community settings, up-skilling of workers involved with Aboriginal communities and for speciality cancer services to make efforts to better engage with Aboriginal communities.

Efforts to promote health literacy in relation to cancer would also be affected by community understandings of cancer as a death sentence. This perception was described as silencing discussion of cancer and distancing some people (resulting from a fear of providing support to family members). The notion of screening, as detecting cancer before it occurs, requires additional focus in this context. While other perceptions of cancer have been described in previous literature focusing on experiences of Aboriginal people with cancer (such as cancer as contagious, a form of punishment or as 'dirty'; McGrath *et al.* 2006b, Shahid

*et al.* 2009a, Prior 2009, Simpson *et al.* 2011), these perceptions were not prevalent in these data.

Pathways for improving understanding of cancer prevalence, treatment and potential outcomes could be informed similarly to those developed for other diseases such as diabetes that have had a longer history of impact on the health and well-being of Aboriginal people (Si *et al.* 2006). However, given the full health agenda (McGrath *et al.* 2006b), the promotion of health literacy in relation to cancer at this point in the history of Aboriginal health and health services will require additional support to reach the same level as other diseases.

The analysis of these data included a reflexive practice, which involved all researchers participating in a workshop forum to discuss these data and their interpretation. Non-Aboriginal researchers were struck by the perception of participants that cancer would not 'touch' their lives. This perception was in stark contrast to the non-Aboriginal researchers' view of cancer as having the potential to affect everyone's lives, including their own. This familiarity with cancer, or an expectation of cancer, along with a sense of hope regarding early detection and treatment, was seen by Aboriginal researchers as wholly different from the experience of the participants in this study. This exchange and reflection seem to parallel the framing and presentation of these results – that is, there are a number of opportunities to promote health literacy in relation to cancer among Aboriginal people, while being aware of the remarkable differences that may exist between Aboriginal and non-Aboriginal people and health systems.

These data provide some insights into the relationship between community knowledge and health service delivery for Aboriginal people. In the community-controlled sector, there is a potential relationship between community concern and misunderstanding (and silence) and the resultant attention that an issue may receive in community health services: that is, the relationship between health literacy of the community and the decisions about health priorities for a community. If the consequences of a health issue such as cancer are only ever dealt with in specialist settings, how can awareness of the potential for this issue to affect the local community be brought back into primary care as a prevention priority? This relationship is further complicated by a perceived absence in the mass media of stories about Aboriginal people affected by cancer. This calls for the speciality organisations and services to improve their relationship with Aboriginal community-controlled health services to raise the profile and understanding of cancer, and to work to better the ways that mainstream services

engage with Aboriginal people and provide practical advocacy for securing attention to this condition among Aboriginal communities. Such a model has been developed in Western Australia with 20% of Aboriginal health workers in that state having attended a cancer education course conducted by Cancer Council Western Australia (Croager *et al.* 2010). Other authors have examined primary care models for remote, rural and Aboriginal communities that may be of assistance for the development of a network of cancer services (Wakerman *et al.* 2008).

Health literacy is a useful concept with which to approach cancer care for Aboriginal communities. When conducting research with Aboriginal people, it is important for researchers to be continually reflexive about the decisions they make in the conduct of research to avoid falling into reiterating stereotypes of Aboriginal people as lacking or deviant (National Health & Medical Research Council 2003). Health literacy is a potentially non-pathologising framework with which to examine Aboriginal people's experience of cancer and to make recommendations for improving this. Health literacy is an internationally recognised (and debated) framework that has been applied in research with mainstream populations, to examine particular needs of immigrant communities and to examine inequities between people in varying socioeconomic groups. However, it enables interpretation that is broader than describing any one group as more or less health literate than another. Health literacy can facilitate recommendations that distribute responsibility for bettering health outcomes, as more recent conceptualisations of health literacy include understandings of social and structural factors. Hence, systems and organisations identified as social and structural influences on health literacy, including the design and delivery of health-care, have a responsibility to be involved in programmes to enhance individual and community health literacy. This is the intention in this study – to examine our data within a broad frame that acknowledges Aboriginal people's historical and contemporary experiences of racism, and the fear and mistrust of health systems that these experiences have bred.

The sampling and recruitment for this study were limited to NSW. We should exercise caution in generalising results from this study to other communities which may have very different historical and current experiences that impact health literacy. Most participants were female and lived in the eastern areas (metropolitan and non-metropolitan) of NSW. These data may be less applicable to men and those who live in more regional or rural areas, particularly those areas with limited health infrastructure. Participation

in this study was through self-selection. The influence of self-selection could be examined in a number of ways: that people who knew more about cancer chose to participate, or that those who wanted to know more about cancer were motivated to participate. We have also chosen in this paper to focus on the consistencies and patterns we observed in the data, rather than on the variability. This does not mean that there was an entirely homogeneous set of perspectives among our participants, and yet, the dominance of the themes we have outlined was very clear, suggesting that there is good evidence here for providing additional investment to both Aboriginal communities and health services to improve cancer experience and outcomes for Aboriginal people.

Cancer is now the second most common cause of mortality among Aboriginal Australians (Australian Institute of Health & Welfare 2011b). However, the findings of this study showed that health literacy in relation to cancer among Aboriginal people (including health workers) requires investment to reach the levels of understanding and skill as achieved for other diseases prominent in Aboriginal communities. Drawing on a body of work that examines health literacy in contexts beyond the immediate clinical encounter, health literacy in relation to cancer for Aboriginal people should be examined as a relationship between the individual, his/her community and Aboriginal health services. Therefore, mainstream and cancer speciality organisations need to work in partnership with Aboriginal communities and services to raise health literacy in relation to cancer among Aboriginal people and health workers.

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