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Title: Health professional's perspectives of the barriers and enablers to cancer care for Indigenous Australians

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Abstract

To investigate health professionals' perspectives about factors that impede or facilitate cancer care for Indigenous people. Semi-structured interviews with twenty-two health professionals involved in Indigenous cancer care. Data were interpreted using an inductive thematic analysis approach. Participants presented their perspectives on a number of barriers and enablers to Indigenous cancer care. Barriers related to challenges with communication, the health system and coordination of care; issues around individual and community priorities and views of cancer treatment; and health professional judgement. Enablers to cancer care related to the importance of trust and rapport as well as health care system and support factors. Results highlight the need for recording of Indigenous status in medical records and a coordinated approach to the provision of evidence based culturally appropriate cancer care. This could go some way to improving Indigenous patient's engagement with tertiary cancer care services.

Keywords: cancer, health professionals, Indigenous, tertiary, qualitative

Introduction

Cancer is the second most common cause of death among Aboriginal and Torres Strait Islander (Australian Institute of Health and Welfare, 2015) (hereon referred to as Indigenous) people with the most prevalent cancers being lung, breast in females, colorectal, prostate and unknown primary site (Australian Institute of Health and Welfare, 2014). Despite Indigenous people having a lower overall cancer incidence than non-Indigenous people they are more likely to have cancers where the prognosis is poorer (Australian Institute of Health and Welfare, 2014). Indigenous people have lower 5 year survival rates for lung, breast, bowel, prostate and cervical cancer than non-Indigenous people (Australian Institute of Health and Welfare, 2013). While there has been a significant decline in age-standardised mortality rates for cardiovascular and respiratory diseases among Indigenous people between 1998 and 2012, the same period saw a 16% increase in mortality rates as a result of cancer (Australian Institute of Health and Welfare, 2015).

In the past ten years, there have been some concerted efforts to understand the reasons for poorer cancer prognosis amongst Indigenous Australians. Differences in prognosis are attributed to lower participation in cancer screening, diagnosis of cancer at a later stage, lower likelihood to receive appropriate cancer treatment, and a higher presence of comorbidities (Condon et al., 2003, Moore et al., 2011, Valery et al., 2006). Additionally, challenges to culturally appropriate communication, lower awareness of cancer and cancer care and different understanding of health and illness among Indigenous people impede patient-provider communication and Indigenous people's participation in the health system (Cass et al., 2002, Shahid et al., 2013, Treloar et al., 2014). Historical interactions with mainstream health institutions continue to contribute to mistrust of the

medical system (Shahid et al., 2009, Treloar et al., 2014) and logistics such as transport, accommodation during medical treatment; expenses related to treatment and travel; and displacement from family all act as barriers to Indigenous people's cancer care uptake and retention rates (Shahid et al., 2011).

While there is a growing body of knowledge about cancer care from the perspective of Indigenous people (Cass et al., 2002, Shahid et al., 2013, Shahid et al., 2009, Shahid et al., 2011, Treloar et al., 2014) less is known about Indigenous cancer care from the perspective of health professionals directly involved in care at the tertiary care level. This paper reports on data from research investigating health professionals' perspectives about Indigenous cancer patients focusing upon their overall experiences, decision-making in the context of patient comorbidity, Indigeneity and geographical isolation from cancer services, as well as their experiences with patients who did not undertake or complete treatment. This paper focuses specifically on the factors that impede or facilitate cancer care for Indigenous cancer patients from the perspective of health professionals involved in tertiary cancer care.

Methods

Ethics

Ethics approval for the study was obtained through the Human Research Ethics Committees of Northern Territory Department of Health, Menzies School of Health Research and Queensland Health, Darling Downs Hospital and Health Service.

Data Collection

The study employed qualitative research methods to explore tertiary health professionals' perspectives of cancer care provision to Indigenous people in Queensland, Austral-

ia. All health professionals who worked in a tertiary oncology clinic were contacted by email with information about the study and were invited to participate. Health professionals expressed interest in participation to the research team member by reply email and a potential interview time and place suitable to the health professional was established. Prior to beginning the interview a participant information sheet including details about the study was reviewed and informed written consent obtained. All interviews were audio-taped with the participant's permission. The interviews were guided by a semi-structured interview schedule providing a rough outline of topics to be discussed but also allowing participants' ample opportunity to both describe and explain their experiences and perceptions in their own words and on their own terms as well introduce new issues and topics for discussion as they felt relevant. All interviews took place between March and July 2013.

Data Analysis

All interviews were transcribed verbatim. Inductive thematic analysis was employed to elicit explicit meaning from the data (Braun and Clarke, 2006). Early interview transcripts were reviewed by the research team (JM, GG, and JA) to identify initial and unique categories for deeper exploration in forthcoming interviews. Three members (JM, GG, and HW) of the research team employed thematic analysis at intervals throughout the research process to organise the data into a number of discrete categories. Concept maps were used to compare and contrast categories throughout the research process and to consolidate these categories into themes that related to the research aims.

Results

Twenty-two health professionals from a range of professions [including nurses (n=4), medical oncologists (n=6), radiation oncologists (n=5), Indigenous liaison officers (n=2), and allied health practitioners (n=5)] involved in the provision of cancer care services were interviewed. Twenty health professionals identified as non-Indigenous and two as Indigenous. There were 15 female and seven male participants. Ten were aged 25-44years and twelve were aged between 45-64years.

A number of barriers and enablers relating to communication; coordination of care; the health care system; support; and community or patient priorities and views of cancer treatment were elicited from participant's accounts of their experiences, decision-making and perceptions of Indigenous cancer patients and their cancer care.

Barriers

Participants identified a number of barriers confronting Indigenous cancer care provision relating to access to cancer diagnosis and treatment and movement through the cancer care trajectory. Barriers related to communication, cancer care coordination, health care system, individual and community issues and health professional judgment are described below.

Communication

Many participants were uncertain about the effectiveness of their communication with Indigenous cancer patients and were concerned about 'not getting it right'.

At the end of the consultations I fundamentally felt like I wasn't communicating with them because I would use the usual like ways that we talk about pain. (P9)

You know whether it's because of lack of education or because of poor communication on our behalf and to expect them to go through a treatment, yeah I think is another challenge. (P21)

Participants talked about the lack of availability of culturally appropriate cancer information for Indigenous patients and were uncertain about how much and what type of cancer related information to provide.

We can access different language resources ... but there's nothing for the Indigenous population. (P14)

Most participants provided written information for all their patients despite being unsure if it was appropriate. Some participants described finding alternative ways of sharing important information with Indigenous patients; for example, by drawing pictures and diagrams, seeking the help of Indigenous Liaison Officers or referring to internet sites with multilingual information. Some participants were uncertain about Indigenous patient's level of comprehension whilst others reported Indigenous patients being less likely to engage in communication with them.

Several participants shared experiences of communicating with patients whose first language was not English and how that presented challenges for them in conveying important and complex information about the cancer diagnosis, treatment and prognosis. In addition, many participants reported that their Indigenous patients have a different view of their health, illness and more specifically, cancer, than non-Indigenous cancer patients and this presented challenges for them with regards to providing treatment.

I think sometimes we get on this treatment and we forget that people are coming here and it's their life. It's about them, it's about their culture, it's about who they identify with and sometimes it's not about the cancer. And for them you know we think that this is what they need and this is the best treatment for them. But for them it's not. We need to respect that. (P17)

Many participants described having limited experience with Indigenous patients, and questioned their own level of cultural understanding and how this might influence their interactions with Indigenous cancer patients; for example, it was difficult for some participants to understand Indigenous patient's connection to country (the land) and family. Being constrained by limited appointment times was considered by most participants as a significant barrier to developing rapport and good communication with Indigenous cancer patients. In some instances participants acknowledged that this could be a barrier to patients asking questions and sharing concerns about their cancer diagnosis, treatment and prognosis.

So I think we often think we don't have time and I think in the public system there is always a time pressure, it's always very difficult and you know the clinics are always going over. But it's always good to just, if you can, to try to spend those minutes because I think it really pays off. (P9)

Another reported challenge was determining the Indigenous status of patients. This was because other staff and relevant medical charts do not always clearly identify such status. As such, many participants explained that they often assumed Indigenous status based on skin colour, area of residence or language of the patient. Many participants questioned whether being aware of Indigenous status would alter or help their interac-

tions with patients or whether treating everyone the same helped to avoid being culturally inappropriate.

I think sometimes clinicians don't know how to broach that subject either without being 'oh you know they might get offended or perhaps it's not appropriate to bring this up so I'll just talk to them about their cancer and then my jobs done and someone else will deal with that sort of thing. (P1)

Health Care System

A lack of appropriate screening and diagnostic services in primary care for Indigenous people, particularly those residing in regional and remote areas, was described by participants. This was perceived by participants as resulting in a delayed cancer diagnosis or the need for Indigenous people to travel significant distances to access services.

There are obstacles in getting that early diagnosis and then there are real distance problems in getting towards appropriate treatment. (P4)

Participants raised concerns about the lack of adequately trained and appropriate health professionals and specialists in rural and remote areas and the transient nature of rural and remote health workers and doctors was raised as a barrier to the provision of continuity of care and follow up for Indigenous cancer patients.

Some participants questioned the capacity of the health system to provide appropriate and sensitive treatment and follow up health care for Indigenous patients.

Communication would improve a lot if we had a lot more Indigenous trained people with whom they can actually relate a lot better. (P21)

Participants described a 'shared care' arrangement for cancer patients (whereby patients see a team of specialists throughout the treatment phase) and while some explained this arrangement as a positive team approach that enabled relationships across a number of specialists, others described this approach as being a barrier to the continuity of care.

Challenges due to incongruity between a Western medical framework and Indigenous views of health and illness were acknowledged by participants. Tertiary cancer care was described as complex, inflexible and formulaic and as unable to deal with a diversity of patient needs. For example, strict appointment times, patient suspicion of chemotherapy treatments, long periods in hospital away from home, land and community were all seen as resulting in patients feeling isolated and experiencing a loss of identity within the system.

Sometimes I think it's very sort of white sterile atmosphere that we have in hospital here is everything's done to a timetable and everything is done to a routine especially in recent times when funding is a bit short and we have to be accountable for every single dollar (P14)

Coordination of cancer care

Transport was reported by many participants as a barrier for patients with regards to attendance and completion of treatment; particularly those who live in regional or remote areas. While not reported by many, the financial cost associated with travelling to and from hospital for treatment and follow-up care was perceived as a salient issue for Indigenous patients, particularly for those on lower incomes.

...having to come back and forward financially strains ... the financial strain on the family yeah as well. (P5)

Participants reported the lack of appropriate accommodation for rural or remote outpatients and their support person as a challenge to cancer recovery for Indigenous cancer patients. The added challenge faced by rural and remote patients leaving home, family and community to undergo cancer treatment in an unfamiliar and complex environment with limited contact with family and community was reported.

But his family and his brother in particular really struggled with that and umm with kind of not really helping him with transport and stuff and at home they were kind of leaving him up to his own devices and stuff. (P 2)

In addition, participants reported that patients from rural or remote areas experience more difficulty in bringing a family member or friend for support due to competing work and family commitments.

Individual and community priorities and views of cancer treatment

A number of participants shared examples where Indigenous patients prioritised staying in their community or returning home to their community rather than attending or completing cancer treatment. This was explained by participants as being in direct conflict with their duty of care to their patients.

Often the priorities become about returning home and being in the community whereas I think with non-Indigenous people it's often about prolonging life and getting all the treatment in. So I think it's a different priority in terms of end of life. (P9)

While reasons for not embarking upon or completing cancer treatment were often not well understood by participants, they perceived many Indigenous cancer patients as

having other existing priorities such as family and community commitments that competed with the requirements of cancer treatment. Other participants explained that patients questioned whether the treatment was worthwhile, were fatalistic and accepted dying from cancer, or, for reasons unknown to the participant, made the decision to not undergo or complete cancer treatment.

Some patients actually I can't believe how accepting all Indigenous patients are, just saying this is my lot in life, this is what I've been dealt and I'm dealing with it. And you know I respect that. (P14)

While acknowledging that some patients experience feelings of isolation and frustration with the health systems and resisted extended hospital stays, a number of participants did describe how some Indigenous cancer patients fully accept their cancer diagnosis and committed themselves to the treatment. Participants described how persistent and strong associations between cancer and death as well as feelings of shame around cancer still exist among many Indigenous people which may impact on their decisions to engage with the health system and cancer care.

This sort of community attitude that you know it's not good to have cancer; it's a death sentence you know point the bone sort of thing. But I think you need to get a lot more people through things to actually convince the community that you know you can do things for them. (P4)

Health professional judgment

Some participants described feeling powerless to influence factors outside of cancer treatment that could improve Indigenous people's participation in and completion of treatment.

I think it can be difficult from the health side though because you feel quite powerless to change those other factors outside whether they're going to influence on what the treatment is. Because often it's not fixable ... what can you do? (P8)

While participants emphasised the importance of providing gold standard care (ie: treatment based on evidence based protocol for chemotherapy and radiotherapy), several examples were given where treatment was modified due to concerns about Indigenous patients not returning for ongoing treatment.

If you've got someone with a locally advanced head and neck cancer and you know that you've got to get that treatment in, you may adjust your technique so that you're getting a good dose in more quickly so that you are going to benefit that patient knowing that he may not turn up every day. (P7)

Enablers

A number of enablers relating to cancer care provision across the cancer trajectory for Indigenous patients were raised by participants. These enablers related to building trust and rapport, the health care system and support factors.

Building trust and rapport

The importance of honesty, openness and building trust and rapport with all patients was described as an important enabler for positive communication and development of

therapeutic relationships. Some participants emphasised this more so for Indigenous patients. Adequate time for appointments, patient-centred care and working in a multi-disciplinary team were all considered by participants as integral to providing numerous opportunities for relationship development with staff and to reduce barriers for patients.

Fit and sense of belonging ... I think it's yeah it's just a trust (P10)

We try and have the consciousness of not you know not setting up in a power differential sort of scenario (P16)

In contrast to comments about the ineffectual nature of cultural awareness courses, several other participants described the importance of these courses in providing an understanding of different cultures and basic information about health system processes and services available to both health professionals and patients. The presence of an Indigenous Liaison Officer or Aboriginal Health Worker who was known to Indigenous patients was considered crucial for assisting communication and helping patients feel at ease. More broadly, developing ongoing relationships between the Indigenous communities and health professionals was described by participants as important for promoting trust and understanding between Indigenous patients and health care providers.

I think because they were so close to the community workers ... this is what I experienced was the community did listen. And there were certain Elders within the community as well who had really close relationship with the health practitioners. And so they actually could bring people to them and that I think made a huge difference. (P14)

Participants expressed the importance of support from Indigenous patients' families to help in the ongoing management of treatment and follow up stages of cancer care including practical help regarding coordination of appointments, medications and transport as well as help facilitating a supportive and understanding environment.

Health care system and support

Due to the health system being complex and unfamiliar for many Indigenous patients, participants suggested patients would benefit from being guided through the health system by a dedicated nurse or a familiar person who has knowledge of the health system.

I can see someone who felt very, not comfortable in the process or totally unfamiliar with a big complex tertiary hospital I think for many people I'd like them to have a chaperone. (P16)

Patients with strong social support throughout the treatment process were described by the participants as being more accepting and more likely to undergo and complete treatment. Patients were considered more engaged in the treatment process and follow up cancer care by participants if they were seen as receiving significant psychosocial support from family and friends. Support and understanding of cancer and cancer treatment by the community, was also mentioned as integral to the patient's wellbeing.

I guess the ones that have good family and social supports, my experience is that they've actually been more accepting of just getting on and doing what they need to do, than non-aboriginal patients (P13)

Discussion

A range of factors were reported by the health professionals as barriers and facilitators to Indigenous people's engagement in tertiary cancer care. The importance of culturally appropriate and coordinated cancer care, patient-provider trust and rapport, culturally appropriate patient-provider communication and strong psychosocial support from family and friends throughout the treatment trajectory were all salient issues raised by participants.

The importance of culturally appropriate and coordinated cancer care is consistent with previous work that identified differences in language, understanding of health and illness and historical experiences with the health care system as barriers to health care utilization by Indigenous people (Cass et al., 2002, Shahid et al., 2013, Treloar et al., 2014). Despite recent emphasis on the provision of culturally appropriate health care and increasing evidence to suggest that such provision leads to better engagement in the health system and ultimately better health outcomes amongst Indigenous people (Council, 2012, Scrimgeour et al., 2008), the ability of mainstream health services to adequately meet the needs of Indigenous people remains in question (Durey and Thompson, 2012, Dwyer et al., 2011). Following an analysis of the links between health assessment uptake and Aboriginal community and organizational engagement in health reforms, Kelaher et al. (Kelaher et al., 2014) concluded that 'stronger links between Aboriginal organisations and between mainstream organisations working with Aboriginal organisations' can improve engagement with the health system and therefore, health equity. However, improvements at the operational level within tertiary health care are largely lacking (Dwyer et al., 2014). Participants in our study identified a number of issues that challenge these improvements including difficulties in identifying Indige-

nous status; a lack of cross cultural knowledge amongst health professionals; and a lack of time during appointments to build rapport, identify patient concerns, and guide patients through what is interpreted as a complex and rigid system. In addition, although health professionals were aware that the fear of a cancer diagnosis, mistrust of the health system and challenges to transport and accommodation existed for Indigenous cancer patients, they did not feel able to address these issues within the scope of their practice and care due to a lack of support and resources.

Consistent with recent studies (Dwyer et al., 2014, Newman et al., 2013), participants in our study explained that providing standard care for all or by treating all patients the same within the limits of the existing system helps to manage the complex needs of a diverse population. However, it has been identified that complex, multi-dimensional approaches to care and service provision are required to address complex needs of some Indigenous patients (Dwyer et al., 2014). For example, drawing upon the findings outlined in our study, complex approaches could encompass addressing transport and accommodation arrangements, a dedicated patient navigator to support patients from pre-admission to post-admission, provision of interpreter services, mechanisms for including family and/or community members in supportive roles, specialist outpatient services in regional areas, development of close relationships between tertiary and primary care providers to ensure coordinated outpatient and follow up care and professional development to improve skills and knowledge of cancer care staff to promote provision of culturally safe health care. In addition, changes should be integrated within all sectors of the health system to improve cultural competency policy and practice at the service level (National Health Medical Research Council, 2005). Cultural competency or cultural safety programs across all levels of the health system from service to policy are an

area that merits further research to improve service provision and patient outcomes for Indigenous people (Mooney et al., 2005, National Health Medical Research Council, 2005).

A strength of the study reported here is the inclusion of a range of health care professionals involved in the cancer care for Indigenous cancer patients at a major tertiary hospital. A main study limitation is that not all health professionals working with Indigenous patients at the hospital were interviewed as not every health professional responded to the email inviting participation. In addition, it must be acknowledged that the results presented here are the perspectives of the health professionals included in this study and may not be representative of all health professionals, in particular those in regional centres.

In conclusion, findings from this study highlight the importance and possible benefit of recording Indigenous status in medical records and the need for a coordinated approach to the provision of evidence based culturally appropriate cancer care. Specifically, improvements in health professionals' cross cultural knowledge and skills; provision of a dedicated patient navigator to negotiate the complex health care system; and improved links between Indigenous communities, Indigenous health care providers and mainstream cancer care services could go some way to improving Indigenous patients' engagement with tertiary cancer care services.

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Conflict of Interest Statement

The authors have declared that no conflict of interest exists.

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