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Aboriginal people in Australia: A qualitative study**

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Published

2016

Journal Title

BMJ Open

DOI

[10.1136/bmjopen-2015-010909](https://doi.org/10.1136/bmjopen-2015-010909)

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# BMJ Open Factors contributing to delayed diagnosis of cancer among Aboriginal people in Australia: a qualitative study

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**To cite:** Shahid S, Teng T-HK, Bessarab D, *et al.* Factors contributing to delayed diagnosis of cancer among Aboriginal people in Australia: a qualitative study. *BMJ Open* 2016;**6**:e010909. doi:10.1136/bmjopen-2015-010909

► Prepublication history for this paper is available online. To view these files please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2015-010909>).

Received 22 December 2015  
Revised 19 April 2016  
Accepted 10 May 2016

## ABSTRACT

**Background/objectives:** Delayed presentation of symptomatic cancer is associated with poorer survival. Aboriginal patients with cancer have higher rates of distant metastases at diagnosis compared with non-Aboriginal Australians. This paper examined factors contributing to delayed diagnosis of cancer among Aboriginal Australians from patient and service providers' perspectives.

**Methods:** In-depth, open-ended interviews were conducted in two stages (2006–2007 and 2011). Inductive thematic analysis was assisted by use of NVivo looking around delays in presentation, diagnosis and referral for cancer.

**Participants:** Aboriginal patients with cancer/family members (n=30) and health service providers (n=62) were recruited from metropolitan Perth and six rural/remote regions of Western Australia.

**Results:** Three broad themes of factors were identified: (1) Contextual factors such as intergenerational impact of colonisation and racism and socioeconomic deprivation have negatively impacted on Aboriginal Australians' trust of the healthcare professionals; (2) health service-related factors included low accessibility to health services, long waiting periods, inadequate numbers of Aboriginal professionals and high staff turnover; (3) patient appraisal of symptoms and decision-making, fear of cancer and denial of symptoms were key reasons patients procrastinated in seeking help. Elements of shame, embarrassment, shyness of seeing the doctor, psychological 'fear of the whole health system', attachment to the land and 'fear of leaving home' for cancer treatment in metropolitan cities were other deterrents for Aboriginal people. Manifestation of masculinity and the belief that 'health is women's domain' emerged as a reason why Aboriginal men were reluctant to receive health checks.

**Conclusions:** Solutions to improved Aboriginal cancer outcomes include focusing on the primary care sector encouraging general practitioners to be proactive to suspicion of symptoms with appropriate investigations to facilitate earlier diagnosis and the need to improve Aboriginal health literacy regarding cancer. Access to health services remains a critical problem affecting timely diagnosis.

## Strengths and limitations of this study

- This paper highlights multiple factors impacting on timely diagnosis of cancer that health professionals should recognise.
- Multiple factors classified into the following main themes were identified: contextual (socioeconomic deprivation, historical/political (impact of colonisation, racism), health system (reduced access to health services, especially for rural patients), patient factors (shame, embarrassment, fear, psychological trauma, male stoicism).
- Solutions need to focus on patient and health system factors.
- Findings from this qualitative study can inform interventions to improve timely diagnosis and shorten interval from symptom presentation to medical consultation.
- Women constituted the majority of participants, so the findings, especially those based on cancer service provider interviews, are likely to reflect the perspectives of female service providers.

## INTRODUCTION

Cancer has overtaken cardiovascular disease as the leading cause of mortality in Australia.<sup>1</sup> Early presentation, timely diagnosis and treatments are critical factors in improving long-term survival for patients with cancer.<sup>2</sup> Thus, reducing delays in diagnosis of cancer is a priority.<sup>3</sup> A new model of diagnostic delay identified patient, healthcare system and tumour factors within the primary and hospital-based care settings interact to contribute to delays in diagnosis,<sup>4,5</sup> so identifying and understanding these are important to developing strategies and programmes to address such diagnostic delay. Poor knowledge, awareness and failure to recognise symptoms,<sup>6</sup> negative beliefs about cancer outcomes<sup>7</sup> and fear of consultation<sup>8</sup> are some of the factors why patients delay in seeking medical attention. Limited access to



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appropriate health and specialist services for patients with cancer in rural and remote locations is one of the known system factors that affects patients living in those locations.<sup>9 10</sup> Several studies highlighted the importance of psychological factors on patients' perceptions, interpretation of symptoms and motivation to go to the doctors and get checked.<sup>11 12</sup> The level and intensity of worry, fear, anxiety, denial, shame and embarrassment have also been explored to understand patients' decision-making processes and readiness to seek help for their symptoms.<sup>12</sup> However, there is a dearth of research regarding health service and/or system factors contributing to delay in care-seeking for cancer.<sup>13</sup>

Advances in medical therapy and interventions have led to declines in cancer mortality in the last decade. However, not all subpopulations have benefited equally from such medical advances.<sup>14 15</sup> Late presentations and higher mortality from cancer have been found among people of lower socioeconomic background and from ethnic minority populations.<sup>12 15</sup>

Aboriginal<sup>1</sup> Australians suffer from significantly higher incidence of aggressive cancers and 69% excess mortality compared with the general population.<sup>16</sup> Aboriginal Australians are over-represented in the lowest quintile of socioeconomic status.<sup>17</sup> Life expectancy of Aboriginal Australians is 10–14 years less than that of non-Aboriginal people,<sup>17</sup> with 70% of the gap in health outcomes due to chronic diseases.<sup>18</sup> Cancer has become the second leading cause of death among Aboriginal people. Advanced cancer at diagnosis, lower cancer survival, reduced access to/uptake of treatment,<sup>19</sup> higher comorbidities, lower socioeconomic status<sup>17</sup> and language barriers are some of the factors that lead to poorer outcomes from cancer in Aboriginal Australians. Aboriginal patients present with cancers with a poorer prognosis (eg, liver, lung, cervical), and participation rates in cancer screening programmes have also been reported to be lower in Aboriginal patients.<sup>20</sup> Hence, a focus on earlier diagnosis and subsequent intervention is important in improving the cancer outcome of Aboriginal people.

A qualitative study was conducted to understand the experiences of Aboriginal patients with cancer in Western Australia (WA). One of the key objectives was to identify factors that can influence patients' decision-making to seek first medical consult. Qualitative research is considered as the lone 'vehicle' for in-depth investigation of factors that impact on how people interpret and act on their symptoms.<sup>21</sup> This paper presents factors contributing to late diagnosis of cancer for Aboriginal patients from patient and health service providers' perspectives.

Our findings are based on Aboriginal people in WA. However, systematic reviews<sup>15</sup> have suggested that

patients with different types of cancer and from different countries share similar help-seeking experiences. Moreover, Aboriginal Australians also share many of the similar clinical, sociodemographic and historical characteristics with other Indigenous populations around the world.<sup>22–24</sup> A recent systematic review exploring factors affecting cancer treatment decision-making among Indigenous people confirmed the dearth of international literature in this area.<sup>25</sup>

## METHODS

### Settings

WA, the largest state of Australia, covers approximately one-third of the continent and is home to the third highest number of Aboriginal Australians (13.2%), of which an estimated 41% live in remote locations.<sup>17</sup> Australia has a universal healthcare system with free public acute hospital services, while allowing choices through a mix of public and private healthcare service providers. The health insurance scheme (Medicare) funds free universal access to public hospital treatment and subsidises out-of-hospital medical consultations and pharmaceuticals. Despite these subsidies, barriers to specialist consultations remain for socially disadvantaged groups, particularly where upfront cash payments are required. Owing to the lack of sophisticated diagnostic facilities and oncological services in rural/remote WA, rural patients with cancer need to travel greater distances to the Metropolitan area of Perth to access cancer treatment. In acute or emergency settings, transfers from rural/remote areas to metropolitan hospitals use the Royal Flying Doctor Service. The majority of Aboriginal people lack private medical insurance making them reliant on effective publicly funded services.<sup>26</sup>

As a group, Aboriginal Australians experience multiple social disadvantages.<sup>27</sup> The legacy of colonisation and dispossession of land to which Aboriginal people have significant spiritual attachment and consequent oppression and alienation are major macro-level (political and environmental) factors that have had huge adverse impacts on the lives of Aboriginal Australians.<sup>28</sup> Perpetuation of the disadvantages also relates to contemporary structural and social factors: economic opportunity, education, employment, income, housing, access to services, social networks, connection with land, racism and incarceration.<sup>29</sup>

### Study design, recruitment and data collection

The study was informed by the hermeneutic phenomenological framework as described by Max van Manen.<sup>30</sup> Considering the context of research with Aboriginal Australians, considerable effort was made to build trust and relationship with the Aboriginal participants prior to conducting this research. An Aboriginal Reference Group was formed and the research plan was presented to the group, discussed and approved. In-depth

<sup>1</sup>In this paper, the term Aboriginal has been used to refer to the Indigenous people of WA. We have used Indigenous when we refer to Indigenous peoples from other countries.

interviews using an open-ended and exploratory semi-structured interview schedule were undertaken with Aboriginal patients with cancer and/or family members and health service providers (HSPs). Service providers' interviews were conducted in two phases—between March 2006 and September 2007 as part of SS's doctoral studies and April and October 2011 as part of a postdoctoral research project to document any change that had occurred between the two periods. All of the Aboriginal patient and family members and most HSP interviews were conducted face to face by SS, with six HSP interviews conducted over the phone. HSPs having experience working with Aboriginal patients were recruited from a variety of service settings in Perth and six rural/remote regions of WA, either purposively or through snowballing. SS, a trained non-Aboriginal, female qualitative researcher, conducted most of the interviews. SS trained one research assistant to conduct some rural/remote interviews and the female research assistant conducted 10 interviews with the HSPs. All participants provided informed consent. Interviews varied considerably in length, commonly lasting around 1.5 hours. Detailed methodology and the protocol have been described elsewhere.<sup>31</sup>

Aboriginal participants were asked to describe their or family members' experiences with cancer and cancer services, with specific interview probes on diagnosis, treatment and follow-up. Service providers' interviews covered questions around their general experience with Aboriginal patients with cancer, specific issues they face and possible solutions to these issues. 'Delayed diagnosis' was identified as a problem from the literature,<sup>19</sup> so possible reasons were explored. For the purpose of this paper, we have kept the original words of the participants to enable retention of their voice.<sup>32</sup>

Qualitative methods are oriented towards understanding rather than simply measuring phenomena. Open-ended data collection allowed research participants to express their views in their own words. Qualitative research is also deemed appropriate for people from a socioeconomically vulnerable subpopulation, especially for Indigenous populations around the world.<sup>33</sup>

### Data analysis

The design, framing and analysis of this research were based on the philosophical foundations of the social constructionist perspective,<sup>34</sup> which considers how people interpret and make sense of their experiences within a particular sociocultural, political and historical context.<sup>35</sup> The interviews were digitally recorded, transcribed verbatim and imported into NVivo software. Transcripts were read repeatedly to understand what was said and to generate 'ideas' about possible descriptive coding categories from the data. An inductive approach was used to identify recurrent categories from participants' responses which were then ordered, recorded and stored as 'nodes'.<sup>36</sup> Alongside the coding process, data were reread by at least two members of the research team to examine how the

codes can be linked to form coherent themes.<sup>37</sup> Finally, underlying categories were refined and grouped, forming an emergent thematic framework.

## RESULTS

### Participant characteristics

Of the participants, 30 were Aboriginal patients with cancer and family members (14 patients with cancer/survivors and 16 family members). In total, 19 (63%) were from rural/remote communities and 11 were from urban areas. The HSPs (62 in total) comprised general practitioners (GPs)/clinic nurses (29.0%), oncologists (3.2%), Aboriginal health workers (19.3%), cancer nurse coordinators (8.1%), palliative care providers (17.7%), social workers (11.3%) and others (11.3%). Forty-five of the HSPs were non-Aboriginal and about equal proportions of all HSPs were recruited from urban and rural settings (table 1).

### Qualitative findings

Three main themes were found to be contributing to the delay in diagnosis: contextual, health system and patient-related factors.

#### Theme 1: contextual factors

Broader socioeconomic, historical and political backgrounds define the context of a population group and determine their connection with the society. Patients' beliefs, knowledge, understanding and interpretation around overall health, patients' social networks and

**Table 1** Demographic information about the health service providers (HSPs)

Positions or roles	Number	Per cent
Clinical (nurses and GPs)	18	29.0
Oncologist/radiation oncologist	2	3.2
Aboriginal liaison officers/Aboriginal health workers	10	16.1
Cancer nurse coordinators	5	8.1
Social workers	7	21.2
Aboriginal community health nurse	2	6.9
Palliative care providers	11	17.7
Others	7	11.3
Total	62	
Place		
Urban	33	53.2
Rural	29	46.8
Total	62	
Gender		
Female	51	82.3
Male	11	17.7
Total	62	
Aboriginality		
Aboriginal	17	27.4
Non-Aboriginal	45	72.6
Total	62	

GPs, general practitioners.

their relationship with health services and approachability, accessibility, availability, affordability and interpretation of appropriateness of health services are all shaped by these contextual factors. These factors are discussed below under two subthemes: impact of colonisation and racism and socioeconomic deprivation:

*Impact of colonisation and racism:* Historical treatment and ongoing racism experienced by Aboriginal Australians in their daily lives have had significant negative impact on their trust and health-related communication with mainstream primary and secondary healthcare professionals and services. Although not generalisable to all Aboriginal patients, several participants spoke about their discomfort related to their Aboriginality, based on service providers' attitudes and racist experiences within the health services. Some participants remarked that no matter how caring the doctor or other health practitioner is, it is the patient's past experience of their encounter within the health service overall and their trust of that service that affects their willingness to attend, to adhere to the advice they receive and to re-attend:

When you talk about the hospital system, I can say, yes ... we've been into some of the units at hospitals where you are just looked at—I know that when my sister was having her treatment, we would walk into the chemo unit, being the only three Aboriginal people there, her, myself and her husband, you would have a lot of white people sitting around and they were just staring at you and they don't come and sit next to you. So, when you are talking about the broader systems, yes, there are those barriers there for Aboriginal people. (Urban Aboriginal patient)

One GP recounted an episode where an Aboriginal patient had arrived at the oncology appointment, checked in the receptionist and took her seat. Another patient who arrived after her was then ushered into the clinic ahead of her. The Aboriginal woman was insulted and left the oncology outpatients, and told the GP she refused to attend for cancer treatment. When the GP investigated, she found out that the woman had arrived early for her appointment and the patient who was seen first had an earlier appointment. But based on the woman's lifelong experience of discrimination, it was unsurprising that she attributed this encounter as yet another example of the health system exhibiting bias and prejudice against her as an Aboriginal woman.

*Socioeconomic deprivation:* HSPs pointed out how lower socioeconomic conditions impacted on Aboriginal people's willingness and capacity to access health services and contributed to the delay in cancer diagnosis. Ongoing 'stressors in life' were also seen as responsible for the delay:

When I came to work this morning... I had a reasonable night of sleep, in a warm bed in a house of roof I have made. I got up this morning... I didn't have to scout around for food ... I just opened the fridge, had my breakfast, had a shower, came to work, knew what was

gonna happen next... you supposed to come here...and I felt fairly good. Yes, I know that I suffer from hypertension but I have taken my medication and so for the rest of the day... I could feel reasonably comfortable. But, if you always have got ache and pain, if you are always hungry, then [when] the other things come alone ... you just don't notice until it's too late. Because it's part of that discomfort. (Urban non-Aboriginal HSP)

Several participants, in similar ways, expressed their concerns around the overall life circumstances that affect the health and well-being of Aboriginal Australians.

## Theme 2: health service/system-related factors

The subthemes relate to access to medical services, availability of hospital beds, the absence of overt or limited symptoms, long waiting periods, the lack of a culturally safe environment, retention of HSPs and new foreign-trained health professionals, shortage of Aboriginal health professionals and diagnostic delay in GP clinics.

*Access to medical services:* Low accessibility to healthcare services was a constant issue highlighted by Aboriginal patients (and their relatives) who lived in rural/remote locations, and among the HSPs. Broader health system and health service infrastructure interact with patients' socioeconomic and cultural characteristics to impede access:

It's access to doctors to get a diagnosis .... If you have a lump in your breast or you have PR bleeding and the doctor only comes once every six weeks, then clearly your need gets ... He may only see the sickest people and you may not actually be sick at that time. You've just got a lump or some bleeding but you're not sick, so you tend to not be the person that sees the doctor because people are prioritised. (Rural non-Aboriginal HSP)

If they're out at a remote community...there's not the same amount of medical support,...there are not doctors going there every week and I don't know how often they go... so maybe when they present they might have already [been] symptomatic but when the doctor comes, maybe they've gone off to another community to visit which often happens and so by the time they get back it could be worse. (Urban non-Aboriginal HSP)

Even after presentation, the waiting period for a diagnostic test was reported to be up to 6 weeks, attributed to scarcity of diagnostic and screening facilities in rural areas of WA. For sophisticated diagnostic tests and post-diagnosis follow-up care, patients require to be transferred to metropolitan facilities with the following issues identified.

Patients with no overt or limited symptoms were given a lower priority compared with those with acute or emergency presentations for air transfers to the city via the Royal Flying Doctor Service. As one participant explained:

The same with the flights out for medical care. If there are three or four ladies about to deliver babies and someone with pneumonia, then they're the people that will get on the plane. The person that's coming to have their PR bleeding looked at or their difficulty voiding or something, and she won't get on the plane. So that's one reason. (Rural non-Aboriginal HSP)

Lack of availability of hospital beds for elective procedures also resulted in delays:

With my father when we were down there (metropolitan service), he was supposed to go in and have a test.... Then they rang and said, 'Oh, we've over-booked; we'll have to put it off for two weeks.' I said, 'Can't he just come in and just be checked? Let us know what to expect because he is turning black.' They said, 'Oh, nothing is going to happen in two weeks.' (Rural Aboriginal family member)

A long waiting period for specialist appointments for public patients was also reported. Despite Australia's universal healthcare system, people without private health insurance may face long waiting periods in the public system for specialist consultations or elective procedures, contributing to diagnostic delays:

[For] Medicare ..., if I wanted to get someone to have a colonoscopy, the only place that I could get that done would be in the public hospital system. So, they would have to go on a waiting list, whereas in private you could just book it with a private guy. So, we are limited in what we can do by the economics of it. (Urban non-Aboriginal HSP)

The lack of a culturally safe environment for Aboriginal Australians has long been reported as impacting on Aboriginal peoples' willingness to seek help for their health problems and cancer is no exception to that:

We know the mainstream doesn't really work for our sick people. They are going to hospital because it's a last resort .... They are sick. That's why sometimes it's too late for a lot of Aboriginal people because there is not culturally appropriate cancer clinics or surgeries. (Urban Aboriginal HSP)

*Retention of HSPs and new foreign-trained health professionals:* Recruitment and retainment of health professionals is a huge issue in rural and remote areas and creates challenges for continuity of care of patients with primary care providers.<sup>38</sup> The high staff turnover creates challenges and hinders development of relationship of trust between a doctor and their Aboriginal patients that impacts on patient care-seeking behaviour. Moreover, many medical professionals in those areas are overseas born and not familiar with Australian or Aboriginal culture, or the history of Australia. Thus, they may lack understanding about the past experiences of Aboriginal people and how it has impacted on their health and well-being. Healthcare models also vary between

countries, and the different orientation of medical professionals may impact on how they deal with patients in Australia. A lack of understanding results in communication gaps between mainstream service providers and Aboriginal patients.

[Our] Doctors tend to be overseas trained so their understanding I think of the cultural issues and their kind of knowledge of Aboriginal health is, when they start out, limited. And there's also a high turn-over of doctors, so you know, they're there for a couple of years and then they're gone which then means that you've got to teach or a whole new set of doctors will have to get used to the patients. (Rural non-Aboriginal HSP)

These cultural differences were not only restricted to doctors but also reflected on other health professionals.

We're such a multi-cultural society and in particular in the health field and with nurses because of nursing shortages we've got a lot of nurses that have been employed from overseas that their culture is totally different to the white Australian culture and then even more vastly different to the Indigenous culture and they don't necessarily understand their issues with shyness. The fact that sometimes they'll say yes because they really don't know what you're answering and they'll say yes they understand but they don't necessarily really understand. So the nurse might be, just think, "Okay, well you understand, I'll walk off and I won't give you any more information." But they really didn't know or understand everything that was being said. (Rural non-Aboriginal HSP)

*Shortage of Aboriginal health professionals:* Many respondents commented on the lack of Aboriginal health professionals engaged by mainstream service providers to support Aboriginal patients. One HSP referred it as a huge challenge, commenting that Aboriginal patients need to feel welcomed when they access services and only an Aboriginal staff can do that effectively because "they'd understand the cultures, the land and spirituality of it, we don't. I mean we can read stuff but we don't feel it" (Rural non-Aboriginal HSP). Aboriginal participants affected by cancer consistently reiterated similar messages.

*Diagnostic delay in GP clinics:* Alongside the accessibility, availability, appropriateness and quality issues, non-specific symptoms associated with some cancers led to misdiagnosis by GPs. Symptoms such as tiredness, weight loss, pain, backaches in the absence of more definite classic symptoms were often considered less urgent from patient and system perspectives; this was considered to result in longer delays. Diagnosis was also more difficult with Aboriginal patients in the presence of other comorbidities:

Generally GPs don't look for cancer as the first thing. So they might go through lots of tests and then they might finally decide ... maybe we need to do a little bit more...

backwards and forwards and things happen a little bit.  
(Urban non-Aboriginal HSP)

One Aboriginal participant expressed her anger related to one of her family members regularly visiting the doctor, and eventually being diagnosed while still young with an advanced-stage cancer—and dying quickly. She added they had trusted the doctor's opinion and never questioned him. Four other participants from urban and rural locations reported similar stories of attending doctors with symptoms and the diagnosis being missed.

### Theme 3: Patient appraisal of symptoms and decision-making

This subtheme relates to symptom appraisal, cultural factors, use of traditional medicines, shame and embarrassment, fear and denial, psychological trauma and gender.

*Symptom appraisal:* Many patients were reported as not perceiving the severity of their symptoms. One woman reported ignoring warning signs for 10 months, putting symptoms down to her smoking habits until finally she collapsed 1 day at work, admitted to emergency and diagnosed with breast cancer. After noticing symptoms, several patients said they tried to think of an alternative explanations and waited for the symptoms to go away/to ease. It was common to initially interpret their symptoms as natural changes, presumed to be associated with age or stress. This 'internal dialogue' phase ('debating' their problem in their own mind) was a key factor contributing to the delay in initiation of taking the first step in the help-seeking trajectory.

My mum ... just died last year. She's forty when sick and she said, "But I just couldn't get to the doctor," and she had a fistula, so she was leaking urine. And she thought, "Oh well... maybe... I've had all these kids and I've wrecked my bladder ..." and so when she finally got to us she had a hole between her bladder and vagina that couldn't be repaired and a stage four cervical cancer.  
(Urban Aboriginal HSP)

Non-specific symptoms leading to a diagnosis occurring at an advanced stage of cancer with a poor prognosis are common even among general population. This was often not understood nor easily accepted by Aboriginal community members and reinforced the distrust some Aboriginal people have towards the health system and 'white' doctors.

*Cultural factors:* Social and cultural expectations, beliefs and practices can also indirectly contribute to delays in diagnosis, some Aboriginal people preferring looking after each other over seeing a doctor until an illness was severe. Women often ignored symptoms due to competing demands such as looking after sick family members or children, grandchildren or a large extended family, a cultural tradition that is still prevalent in many Aboriginal communities. There were 'many other

preoccupations' so that time for self was not prioritised. There was varying recognition among health professionals of the multitude of factors that affect an Aboriginal person's life and ability to prioritise their health.

*Use of traditional medicines:* Bush medicine and traditional healing were used for cancer, although often this use was surreptitious. It was reported that many non-Aboriginal HSPs did not understand or often did not want to acknowledge the use of bush medicine in Aboriginal people's lives, not understanding its importance and significance for them. Three non-Aboriginal HSPs expressed their concerns that Aboriginal patients may not be diagnosed because they were taking their traditional medicine and hence die from cancer.

I think late stage because they don't seek medical advice. They don't go to clinics, they tend to use other [medicines], look after each other, like I said. "Oh I got tummy ache,"—"Have a drink of this," Or, that's how I perceive it.  
(Urban non-Aboriginal HSP)

Non-Aboriginal participants expressed their concerns that a tumour could keep growing while Aboriginal patients were on the traditional medicines. Ultimately when they came in for medical attention, they might have an advanced stage of cancer. No Aboriginal participants raised such issues and some commented on people they knew who had remissions and improvements using bush medicine.

*Shame and embarrassment:* Disclosing a cancer diagnosis to family and friends was a matter of shame for some people and regarded as putting some people off seeking advice on their symptoms. Shame, to some traditional Aboriginal people, was associated with a past wrongdoing in the sense that some Aboriginal people might think, "... it's bad I deserve it, I've done something wrong. It's our way of taking that punishment" (urban non-Aboriginal HSP). Owing to cultural sensitivity attached to different body parts, shame and embarrassment were also related to cancer of particular types. Although embarrassment around cancers such as breast cancer is decreasing in Aboriginal communities, attributed to media coverage and public discussion about this cancer, it was reported as remaining for cervical and prostate cancers. Participants from some remote communities mentioned that the breast cancer screening van visiting the community is taken up as a social gathering with women enthusiastically gathering to do the health check-ups and breast screening.

Other forms of primary prevention through screening were reported as being inhibited with Aboriginal people being 'shy to come to the doctors' and not attending until the patients feel very sick. Aboriginal people were reported as not understanding the purpose and importance of screening and not wanting to bother the doctors until they are really sick.

Shame, for some men, was associated with the fear of losing their ‘pride as men’:

He hated everything about the hospitals. He hated the food. He hated being restricted to a bed. He hated having to ask for things when he needed things. He is a very proud man. He is 84 years of age and, yes, a very proud man... a father of 12 kids. (Urban Aboriginal family member)

*Fear and denial:* Emotions such as fear, denial, worry about the diagnosis and after-effects impact on the help-seeking behaviour. Many Aboriginal people did not want bad news, opting to put off seeking help for their symptoms. There was also recognition that ‘cancer treatment makes you sick’, so some people avoided check-ups and care-seeking, not wanting to be diagnosed with cancer and to go for treatments.

I try not to think of it, actually ... laughing .... I suppose it's a bit of denial, isn't it? ... It's one of those things that you hear about all the time, but you always think it won't happen to me .... It's like all these smokers... they hear all about this stuff about lung cancer and all the rest, but it's not gonna happen to them, so they keep smoking .... (Urban Aboriginal HSP)

*Psychological trauma:* Psychological suffering arises from even thinking about a cancer diagnosis for all patients, but for Aboriginal patients, such distress is also related to the ‘fear of the whole system’, and ‘fear of leaving home’ for treatment upon a cancer diagnosis. This is especially true for patients who would need to travel long distances to cancer centres, leaving behind family and country. One participant pointed out, “I think it’s probably just traumatic, ... it’s traumatic for metro people to come to the hospitals and have treatment—but especially rural communities, the whole Perth [city] situation is traumatic” (rural Aboriginal family member). The collective memory of past experiences in the health system can add stress to the whole experience for Aboriginal people and affect their willingness to seek help for the symptoms.

*Gender:* Many participants identified a gender dimension, highlighting that men are reluctant to admit their symptoms and seek medical consultation “knowing it ... depresses and stresses the men” (urban Aboriginal HSP). They added that it is not unique to Aboriginal men but that Aboriginal men may be more reluctant because of their past encounters with health services and gender stereotypes. This was particularly true for older Aboriginal men who had lived their whole life independently; they were often ashamed of admitting that they are unwell and depending on others.

## DISCUSSION

### Primary care sector is key to earlier diagnosis and linkage to cancer service pathways

Early staging is a major prognostic indicator for malignancies; however, Aboriginal Australians often present

with higher rates of regional and distant metastases compared with mainstream population.<sup>39 40</sup> This paper aimed to understand the factors contributing to delay in seeking initial medical consultation for Aboriginal patients with cancer. Several key factors were identified from the study: political/historical colonisation, socio-economic deprivation, patient-related factors, differences in cultural and social values, lack of education as a consequence of sociopolitical and cultural marginalisation by the dominant culture, health system-related factors (with access being a critical issue in rural/remote areas) and patient–provider dynamics. The content in this paper points to the need for solutions in cancer care to focus on the primary care sector to improve the problem with delay in diagnosis and presentation of advanced disease. This would require GPs to instigate earlier and more efficient diagnosis and help expedite them into treatment and encouraging people with symptoms to present earlier and overcoming their fears. A key issue is not to rely on care pathways once the patient has been diagnosed with a cancer and is linked into a cancer service (although there are issues which would help compliance and completion of treatment), but to work with the primary care sector to support more efficient diagnosis of patients with symptoms that are potentially cancerous. However, primary healthcare providers do not often see it as a priority to engage in early detection of cancer unless they are specifically engaged.<sup>41</sup> Enhancing linkages with cancer services may also assist with reducing fear and encouraging adherence and completion to optimal treatment regimes.<sup>42</sup> In addition, doctors need to be aware that in Aboriginal people, the incidence of many conditions occurs at a much younger age than in non-Aboriginal people so that their index of suspicion should be triggered at a lower threshold.

Many of these identified factors are congruent with the qualitative synthesis reported by Smith *et al.*<sup>43</sup> and are quite universal.<sup>13 15 44</sup> However, there is a dearth of literature showing how contextual factors of colonisation, socioeconomic deprivation, health service/system factors<sup>13</sup> and ‘cultural safety’ influence patient’s help-seeking behaviour as are described in this paper. The findings illuminate a point of wider application that decisions regarding the source of care and timing of utilisation are influenced by the characteristics of the cultural and social factors.<sup>45</sup> External factors also have an important role affecting patients’ health-seeking behaviour with health-service related factors explored in depth. Whereas majority of the research studies explained patients’ delays only by highlighting the dichotomy of patient and provider dynamics, this study contextualised ‘health’ in a wider societal context, encompassing structural, cultural, political and economic factors, as it is now acknowledged that “social determinants interact with biological and personal determinants at a collective level to shape individual biology, individual risk behaviours, environmental exposures,



and access to resources that promote health” (p.2).<sup>46</sup> The presence of multimorbidities is also linked to social deprivation.<sup>47</sup> Aboriginal people is a group known to be at ‘high risk’ for several chronic diseases, including some cancers,<sup>48</sup> and to experience disproportionate burden of death, diseases, disability and ill health. Although our findings pertain to Aboriginal people in WA, Indigenous people in Australia and around the world share many similar clinical, sociodemographic and historical characteristics.<sup>19</sup> Furthermore, some of the findings specific to patient-related factors could also be generalised to other collectivist populations and subpopulations with socioeconomic deprivation.

### **Adopting alternative innovative models of cancer care using patient navigators and telehealth services**

The health outcomes of Aboriginal (vs non-Aboriginal) people across Australia are worse across many diseases, and remoteness poses additional health service challenges in closing the gap.<sup>49</sup> Provision of health services is inversely proportional with increasing distance from metropolitan city.<sup>50</sup> The tyranny of distance and lack of transport are major impediments to accessing appropriate primary, specialist and follow-up healthcare in many of rural and remote Australia and consequently contribute to delay in diagnosis of cancer. Furthermore, in the more recent years, Australia has been increasingly reliant on fly-in-fly-out doctors and health professionals from interstate or overseas to cover staff gaps in the country hospitals.<sup>51</sup> This compromises continuity of care, doctor-patient relationships of trust, and understanding of the culture and communication with the Aboriginal people.<sup>38</sup> Furthermore, although Australia has a universal healthcare system, transfers from remote locations to metropolitan health services are less likely to take place for those without private health insurance coverage and for non-emergency conditions.<sup>52 53</sup> Diagnostic delays vary between cancers. Emery and colleagues found a shorter delay where patients were referred to private specialists,<sup>10</sup> but private health services are largely not accessed by patients of lower socioeconomic background due to high ‘out-of-pocket’ cost. Ideally, services need to be brought closer to where Aboriginal people live. Alternative innovative models of cancer care (supporting and resourcing primary care; creating a patient navigator position within the primary care settings; use of telehealth<sup>54</sup> for oncology) should be developed to address barriers related to remoteness. Patient navigator positions, for example, are successfully and widely used in the USA to help people overcome sociocultural barriers and to get them access to adequate healthcare.<sup>55–57</sup> Despite being unregulated until today, the National Association of Healthcare Advocacy Consultants is in the process of developing a nationally recognised set of credentials for patient navigators, which will help formalising the position within the mainstream health system in the USA.<sup>57</sup>

### **Building trust and need for cultural safety training**

Trust is crucial for patients struggling to accept diagnoses and to follow complex treatment plans.<sup>58</sup> In the Australian context, distrust is still embedded within most of the relationship and communication between Aboriginal and non-Aboriginal people due to the historical reasons. Trust-building depends on how mainstream health workers develop an awareness of the impact of colonisation process, their awareness of how their own cultural background and values can impact on their relationship with people.<sup>59</sup> Cultural safety training is often delivered to attune health professionals about the potential adverse effects of the power imbalances between the consumers and healthcare providers on patients accessing the services.<sup>60</sup> Such training also demonstrates that health system works within a political and social context and not just within a scientific, ethical or legal structure.<sup>61</sup> Transparent, respectful and empathetic communication between the HSPs and the patients/families about the diagnostic, treatment and cancer care procedure, longer consultation by the primary care providers, sustainable long-term relationship between the patients and the primary/secondary care staff and development of a person-centred model of care would rebuild the misplaced trust between a lot of Aboriginal patients/families and the non-Aboriginal HSPs, and ensure culturally safe environment.

### **Cancer awareness and health promotion programmes to enhance understanding of cancer in the community**

In terms of patient-related factors, delay in cancer diagnosis has been attributed to the delay in symptom appraisal and lack of understanding of cancer. Importantly, the non-specificity of mild signs and symptoms frequently gets dismissed in the early stage against the background of socioeconomic deprivation and competing needs and demands. These findings are consistent with findings from the international literature.<sup>62</sup> Social inequality therefore is a predictor for delay in diagnosis.<sup>63</sup> This strengthens the previous findings by Ramirez *et al*<sup>44</sup> who reported insufficient strength of evidence to support the association of lower socioeconomic status with delayed presentation of symptomatic breast cancer. Patients even after recognising changes in symptoms are reluctant to take action due to the ‘fear’ factor as cancer is equated with ‘death sentence’.<sup>7</sup> Dubayova and colleagues, in their systematic review, listed out different stages of fear and also identified fear and anxiety as one of the predictors for longer delay.<sup>12</sup> Appropriate health education focusing on the importance of early diagnosis and customised health promotion programmes is necessary to dispel the notion that cancer is a ‘death sentence’ and to overcome fear.<sup>12</sup> Despite the small number of men in our study, it is clear that men require a special focus.

## Use of traditional complementary herbal medicine and its potential interactions with anticancer agents

Use of bush medicine and/or traditional healing is connected to the holistic world view of the people from different cultural backgrounds.<sup>64 65</sup> However, traditional medicine has rarely been systematically investigated and/or reported as affecting the help-seeking behaviour of people experiencing cancer.<sup>66</sup> One study found a statistically significant relationship between the use of traditional complementary and complementary medicine and reported delay in seeking help from clinical medicine ( $p < 0.001$ ).<sup>66</sup> Traditional bush medicine and other alternative healing practices/rituals were found to be commonly used among many Aboriginal Australians, in time of crisis.<sup>64</sup> Similarly, the use of traditional herbal medicines has been well entrenched in certain cultures, such as the Chinese, Indians and Middle Eastern people, for thousands of years.<sup>67</sup> Recognition and understanding of the multifaceted needs of this type of medicine by the service providers can encourage people from different backgrounds to access medical services in time and to share and discuss their preferences which would help them make more informed decision. The healthcare provider needs to discuss the types and use of bush medicine in a gentle and respectful manner to learn if any of the components is likely to interfere with chemotherapy or adjuvant therapies. Clinicians should be vigilant about the potentially adverse, clinically relevant interactions between anticancer drugs and herbal medicines, in patients with cancer who take traditional medicines. Failure to recognise these could lead to dire consequences.<sup>68</sup> The interaction of traditional and Western medicines needs examination as a real issue and not simply dismissed by HSPs.

Women constituted the dominant proportion (82%) of participants; thus, the findings (from HSP interviews) might primarily reflect the perspectives of female service providers. However, the strengths of our study lie in the broad perspectives undertaken with the patients with cancer (or their families) as well as health service professionals from the rural and metropolitan settings.

## Conclusions and implications

Improving cancer outcomes for Aboriginal Australians is a high priority given their well-documented poorer cancer outcomes. The evidence suggests that the greatest potential for improving outcomes from cancer is two pronged: (1) through early presentation to the GPs/healthcare system; (2) improvements in the health literacy of the Aboriginal people. Many of the factors identified in this study are external or system related, and interact with multiple factors related to the social, economic and cultural environments of Aboriginal people. Gaps in diagnosis, treatment and survival between Aboriginal and non-Aboriginal Australians indicate that current programmes and models of service delivery often do not adequately meet the

needs of Aboriginal Australians with cancer. Importantly, the links between primary care physicians, specialists and cancer services need to be further strengthened, particularly for Aboriginal people living in rural/remote Australia.

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**Acknowledgements** The authors thank all the participants for their time and for sharing their experiences with them. They are thankful to many health service providers who assisted in the process, and acknowledge the support they received from Kim Skett, the clinical nurse consultant at Silver Chain, and Colette McKenna and Kathy Deas who assisted with the project implementation. SS is supported by an NHMRC Early Career Fellowship (APP1037386). The Western Australian Centre for Rural Health receives core funding support from the Department of Health and Ageing.

**Contributors** SS coordinated the project, participated in the project's design, carried out the data collection and analysis for this project, and prepared the initial draft. DB, SA and SCT participated in the design, assisted with the conduct of the study, helped interpret findings, commented on drafts of the manuscript and writing. T-HKT and SB actively took part in writing. SB also provided advice as clinician. All authors read and approved the final manuscript.

**Funding** This research was supported by the Suzanne Cavanagh Early Career Research Grant from the Cancer Council of WA and Cancer and Palliative Care Research and Evaluation Unit (CaPCREU) Small Grants Scheme.

**Competing interests** None declared.

**Ethics approval** Human Research Ethics Committee of Curtin University, University of Western Australia, WA Country Health Services and the Western Australian Aboriginal Health Ethics Committee.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data sharing statement** Extra data will be available by emailing: s.shahid@curtin.edu.au.

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