

Review

Factors influencing cancer treatment decision-making by indigenous peoples: a systematic review

Rona Tranberg^{1*}, Susan Alexander¹, Deborah Hatcher¹, Sandra Mackey¹, Shaouli Shahid^{2,3}, Lynda Holden¹ and Cannas Kwok¹

¹School of Nursing and Midwifery, University of Western Sydney, Sydney, New South Wales, Australia

²Western Australian Centre for Rural Health (WACRH), University of Western Australia, Perth, Australia

³School of Nursing, Midwifery and Para Medicine, Curtin University, Perth, Australia

*Correspondence to: School of Nursing and Midwifery, University of Western Sydney, Locked bag 1797, Penrith 2751, Sydney, New South Wales, Australia.
E-mail: r.tranberg@uws.edu.au

Abstract

Objective: We aim to systematically review studies that identify factors influencing cancer treatment decision-making among indigenous peoples.

Methods: Following the outline suggested by the Preferred Reporting Items for Systematic Review and Meta-analysis, a rigorous systematic review and meta-synthesis were conducted of factors that influence cancer treatment decision-making by indigenous peoples. A total of 733 articles were retrieved from eight databases and a manual search. After screening the titles and abstracts, the full text of 26 articles were critically appraised, resulting in five articles that met inclusion criteria for the review. Because the five articles to be reviewed were qualitative studies, the Critical Appraisal Skills Program toolkit was used to evaluate the methodological quality. A thematic synthesis was employed to identify common themes across the studies.

Results: Multiple socio-economic and cultural factors were identified that all had the potential to influence cancer treatment decision-making by indigenous people. These factors were distilled into four themes: spiritual beliefs, cultural influences, communication and existing healthcare systems and structures.

Conclusion: Although existing research identified multiple factors influencing decision-making, this review identified that quality studies in this domain are scarce. There is scope for further investigation, both into decision-making factors and into the subsequent design of culturally appropriate programmes and services that meet the needs of indigenous peoples.

Copyright © 2015 John Wiley & Sons, Ltd.

Received: 9 December 2014

Revised: 9 June 2015

Accepted: 11 June 2015

Background

There are an estimated 370 million indigenous people in more than 70 countries around the world. In this paper, the word ‘indigenous’ is used in a global sense to refer to first nation inhabitants who might also be known as ‘native’, ‘aboriginal’ or another term denoting them as original inhabitants of a country. Although they embody a rich diversity of cultures and traditions, one attribute they do share is marginalisation, particularly in the area of health. Across the globe, the health of indigenous peoples is significantly lower than non-indigenous populations [1]. In 2009, the World Health Organisation endorsed a resolution that reducing health inequities should be a priority for all countries [2]. Yet, indigenous peoples continue to experience higher rates of morbidity and to die at a younger age [3].

Cancer has been identified as one of the primary contributors to health inequities between indigenous and non-indigenous peoples [4]. In Australia, cancer is the second leading cause of death among indigenous people [5], and despite lower incidence rates, the fatality rate is twice as high as for non-indigenous Australians [6]. In

the United States, survival rates are lower for indigenous peoples with cancer; they have lower rates of screening and higher rates of advanced-stage disease at initial presentation [7,8]. Cancer prevalence has been increasing among indigenous peoples in a number of countries at the same time that the cancer prevalence in non-indigenous people has been decreasing [7,9,10]. One phenomenon that is understood about the poorer cancer outcomes among indigenous peoples is the impact of lower rates of treatment uptake [6]. What is not so clearly understood are the reasons for this lower uptake. Undoubtedly, they will be complex and inter-related, but identifying them and how they influence decision-making has the potential to play an important role in cancer outcomes for indigenous peoples. Previous research has already identified a number of factors at the macro level that significantly influence health-related decision-making of indigenous peoples. They include the consequences of colonisation, socio-economic factors and inaccessible and inappropriate health services [6,11,12]. Despite this existing knowledge, the ongoing poor cancer outcomes of indigenous peoples suggest there is much that is not yet systematically known about the factors influencing their decision-making.

The purpose of this systematic review was to identify the factors influencing cancer treatment decision-making among indigenous peoples. There was a single research question – What are the factors influencing the cancer treatment decision-making of indigenous peoples? It is intended to inform a larger research project that will investigate ways of improving cancer treatment uptake and hence cancer outcomes for indigenous peoples.

Methods

The authors discussed the research question and methods until consensus were achieved. The Preferred Reporting Items for Systematic Review and Meta-analysis statement was selected to guide the review because it promotes transparent, consistent and complete reporting of systematic reviews [13].

Eligibility criteria

Publications were eligible for inclusion if they contained the following key search terms: aboriginal or indigenous, cancer, treatment and decision-making. Only publications post-1960 were considered for inclusion because this period has witnessed a shift in patient decision-making from passive acceptance of medical recommendations to becoming more active participants in decision-making [14]. Studies from all countries and settings were included if they were English language reports of qualitative, quantitative or mixed method primary research involving male or female indigenous adults (18 years or older) who had been diagnosed with any form of cancer, or were family or community members or carers of indigenous people with cancer. The decision was made to exclude 'grey literature', dissertations and discussion papers because these sources had not been subjected to the peer review process.

Search Strategy and article selection

With the assistance of a medical librarian, publications from January 1960 to March 2014 were searched through eight electronic databases: CINAHL, Embase, JSTOR, Medline, Proquest, Psycinfo, ScienceDirect and Scopus. The search terms provided to the librarian were the following: aboriginal, indigenous, Native Americans, Maori, Torres Strait Islander, cancer, neoplasm, carcinoma, treatment, traditional healers, herbal medicine, patient and shared decision-making. The librarian further expanded these terms during the search as alternate terms for these key search terms were identified.

The initial database search produced 721 potentially relevant studies. A further 12 articles were retrieved by manually reviewing the reference lists, totalling 733 papers. Duplicates of 128 were removed, leaving 605 articles to be reviewed. The authors (RT, SA, DH, SM, LH and CK) independently screened all records by the

abstracts and titles. They subsequently worked in pairs to agree on the selection and exclusion of articles, resulting in the exclusion of a further 579 articles. These studies were excluded because they did not include indigenous patients as the study cohort; because the primary focus was on health professionals, services or support networks rather than patients; because the study was not about cancer; because the article did not report original research; or because the focus was on research design or indigenous issues in research.

Four authors (CK, SM, DH and SA) reviewed all 26 full text articles individually then all authors met to confirm or reject articles for inclusion. A further 21 articles were excluded in this process, leaving five papers to be included in the systematic review. Reasons for exclusion of articles at this stage were that the variables influencing decision-making were pre-determined by the authors so the articles examined the influence of these variables rather than identifying factors influencing decision-making; the article focused on instrument development; or the focus was on screening for cancer rather than treatment. The search and selection process is illustrated in Figure 1.

Quality assessment

The methodological quality of the selected publications was assessed using the Critical Appraisal Skills Program (CASP) instrument for qualitative research [15]. The use of standardised checklists such as the CASP instrument helps to identify bias in individual studies and across studies, enhancing the quality of the review [16]. Three of the reviewed articles scored 100%, while two articles failed on one criterion each. One did not clearly identify the recruitment strategy [17], while another did not identify whether the relationship between researcher and participants had been adequately considered [18]. Table 1 includes details of the included articles.

Data extraction and synthesis

All five of the included studies were based on qualitative methodology; hence, data extraction and analysis were necessarily qualitative. This process was guided by the methods for thematic synthesis of qualitative research in systematic reviews developed by Thomas and Harden [19]. Four of the authors (SA, CK, DH and SM) individually extracted the findings and conclusions from the included studies. Thereafter, they came together in pairs to compare and confirm the findings and themes extracted. Subsequently, all authors were involved in the process of grouping the findings from the original studies into categories according to similarity of names and meanings. Further discussion and category refinement resulted in the identification of nine categories of findings that were clustered to produce four synthesised findings that can

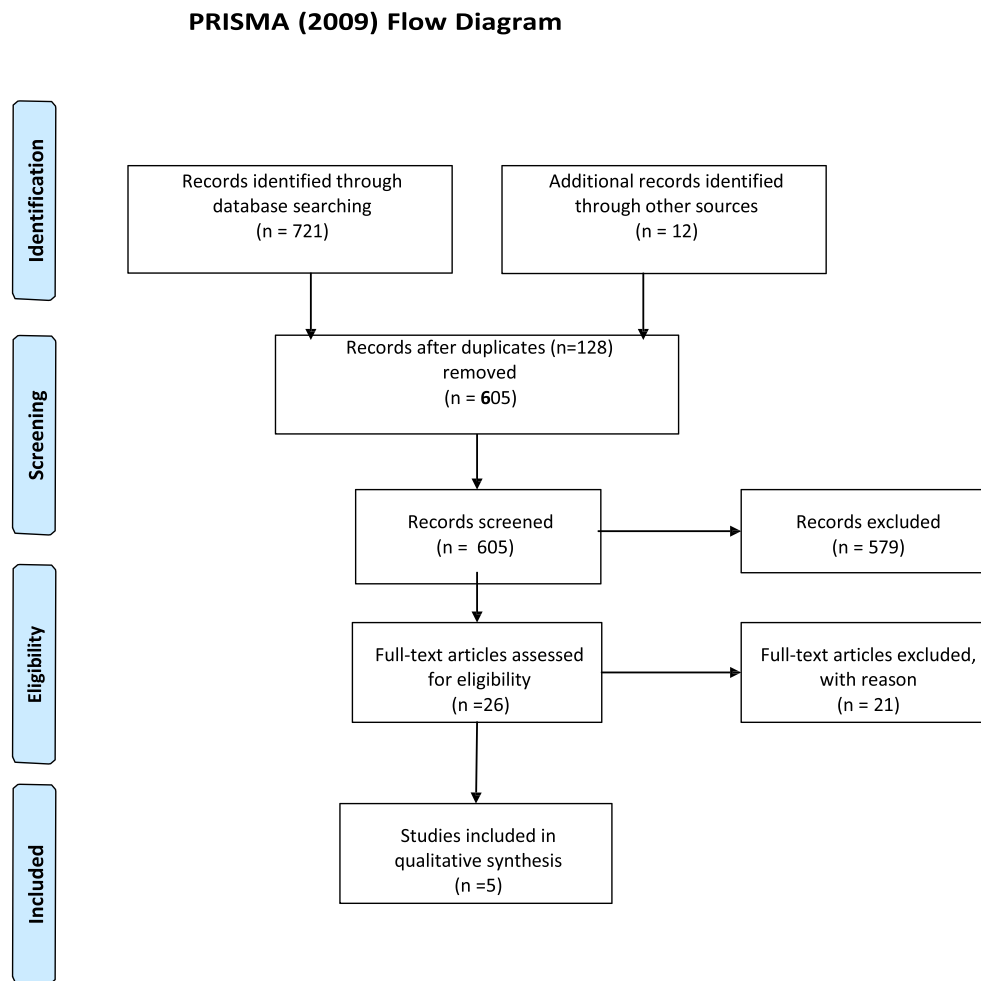


Figure 1. Preferred Reporting Items for Systematic Review and Meta-analysis (PRISMA) flow diagram

be used as a basis for formulating recommendations for practice. See Figure 2 for identification of themes and sub-themes from the review.

Results

Five papers published between 2000 and 2013 were included in the systematic review. All of the studies were conducted in Australia. All collected data from both male and female participants. Four studies included healthcare providers and Aboriginal health workers [17,20–22], and four included family and community members as participants [17,18,20,22]. All five studies were conducted in two states and one territory of Australia, with two being conducted in rural or remote areas [20,22]. One study [21] focused only on treatment decision-making associated with breast cancer, another on vulvar cancer [20], while the remaining three reported on cancer in general [17,18,22]. Two of the included studies were conducted by the same group of researchers, one of whom (SS) is a co-author on this paper. To avoid any conflict of interest, SS did not contribute to the article selection processes or participate in the data analysis and synthesis.

While all five reviewed studies identified as ‘qualitative’ methodology, only the study by Prior [22] gave details of the specific interpretive ethnographic approach that underpinned the research. All reviewed studies employed interviews and focus groups to collect data, which were then analysed either thematically or through content analysis. The majority of the studies ($n=4$) reported themes supported by quotes from participants. However, in view of the sensitive nature of the vulvar cancer reported in the study by McGrath and Rawson [20], findings were presented via author narrative in order to protect participants’ identities.

The themes identified by this review were the following: spirituality, cultural influences, communication and existing healthcare systems and structure. These themes and their associated sub-themes are illustrated in Figure 2 and described in the succeeding text.

Theme I: Spirituality

The concept of spirituality is difficult to define. Whether one takes a religious, philosophical or a secular approach, cultural beliefs and social conventions all influence the

Table 1. Articles included in the systematic review

Author, date (listed in date order)	Aims	Participants	Recruitment locations	Data collection	Data analysis	Themes/key findings	Quality scores (CASP)
McMichael et al., 2000	Identify social, structural and personal factors associated with the detection, treatment and post-treatment care of breast cancer	101 Aboriginal women in target age group for breast cancer screening; Aboriginal women with history of breast; and eight Aboriginal men	Queensland Australia – urban, rural and remote areas	Case study, in-depth interview and focus group	Thematic analysis	<ul style="list-style-type: none"> Health was mediated by personal experience and social, historical, cultural and structural factors Most women could describe one symptom of breast cancer Women lacked confidence in breast self-examination and did not self-examine regularly Attitudes to breast screening services were influenced by access to and location of services Information about diagnosis and treatment options was complex Treatment is disjointed and the process is disorienting Avoidance of breast reconstruction and prostheses Counselling helps women adjust but is not always appropriate 	10/10
Prior, 2009	Explore why Aboriginal women participate in cancer screening programmes but appear reluctant to follow up and accept advice about treatment	48 – 13 Aboriginal women with history of cancer; 25 Aboriginal women involved with experiences of others; 10 Aboriginal and non-Aboriginal health care providers	Two rural Aboriginal communities in Queensland, Australia	Participant observations, interviews and fieldwork	No specific data analysis method mentioned, but the outline of analysis process suggested thematic analysis	<ul style="list-style-type: none"> Perception – cancer diagnosis is a death sentence; fatalistic view of cancer Believes cancer is a dirty disease Cancer a manifestation of bad spirits Concerns about treatment – feelings of shame and separation from family Invasive treatment threatens identity Christian beliefs about the sacred body Cultural perspective – only recently accepting of palliative care 	10/10
Shahid et al., 2009	Explore Western Australian Aboriginal peoples' perceptions, beliefs and understanding of cancer:	37 – 14 Aboriginal cancer patients or survivors; 16 family members; and seven health service providers	Three rural/remote and one urban location in Western Australia	In-depth interviews	Thematic analysis	<ul style="list-style-type: none"> Attribution of cancer to spiritual causes Fatalistic expectations about cancer Unrealistic expectations of treatment Cancer is contagious Limited understanding of cancer Perceptions of cancer screening were limited Urban and rural/remote differences not related to geography Bush medicine and traditional Aboriginal healing widely reported 	9/10
Shahid et al., 2011	Explore differences in experiences for Aboriginal people based upon their residence in urban, rural or remote settings	30 – 14 Aboriginal people with history of cancer and 16 family members	Urban and remote areas in Western Australia	In-depth, semi-structured interviews	Thematic analysis	<ul style="list-style-type: none"> Transport problems Accommodation problems Concerns about the Hospital environment Expense of medication and treatment 	9/10

(Continues)

Table 1. (Continued)

Author, date (listed in date order)	Aims	Participants	Recruitment locations	Data collection	Data analysis	Themes/key findings	Quality scores (CASP)
McGrath & Rawson, 2013	Explore the experience of vulvar cancer from the perspective of Aboriginal women and the health professionals who care for them in the Northern Territory, Australia	40 – 12 Aboriginal women with vulvar cancer; 14 Aboriginal health workers; 10 nurses; three doctors; and one community member	East Arnhem, a remote area of the Northern Territory.	In-depth, open-ended interviews	Thematic analysis	<ul style="list-style-type: none"> Lack of Aboriginal support and liaison workers Some positive support experiences Vulvar cancer is a private female issue Diagnosis of vulvar cancer is associated with shame, fear and worry 	10/10

CASP, Critical Appraisal Skills Program.

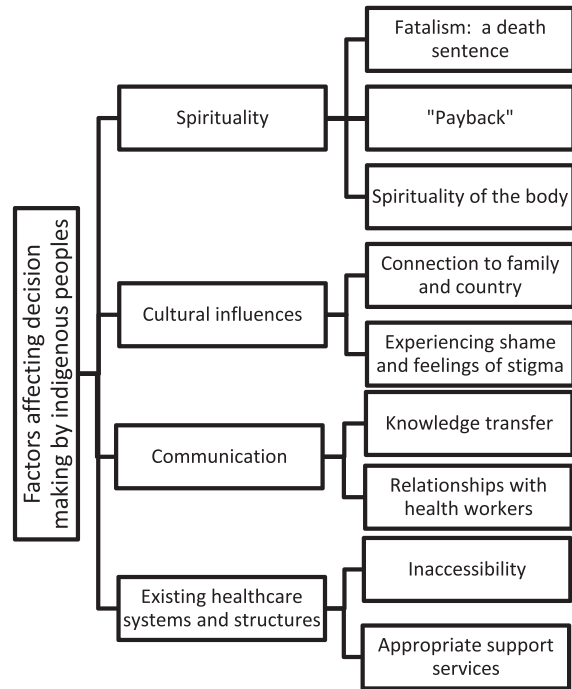


Figure 2. Themes and sub-themes identified from the reviewed articles

way this concept is understood [23]. Broadly speaking, spirituality relates to the meaning of life, to what is important in a person’s life and death, and spirituality has major influences on the individual, family and community beliefs and practices of indigenous peoples. It was not surprising, therefore, that spiritual issues, identified as fatalism, payback and spirituality of the body, were significant considerations in making decisions about cancer treatment.

Fatalism represented an overriding belief that cancer is a death sentence [24]. Participants were able to identify members of their families who had died from cancer, but not many who had survived.

‘I saw my Mum go through chemo and radiation ... I saw my baby brother go through it. I [*sic*] seen my first cousin goes through it, and all my aunties all had cancer ... They have all passed away with cancer’ (family member) [17].

Because of the perception of cancer as a death sentence, there was a belief that it was beyond the capacity of an individual to control cancer or influence the outcome.

‘It’s sort of like your world crumbles. All we know about cancer is you die from cancer, not so much that cancer can be cured. You always know that as soon as you get cancer you are gone ..., you are a goner’ (family member) [17].

Following this line of thinking, active cancer treatment was frequently perceived as pointless because it was believed that nothing could alter the outcome.

'I don't think that it's something you can prevent, it's just people are chosen ...' (participant not identified) [17].

This perception of being 'chosen' or selected was also illustrated in Prior's [20] research when participants spoke about 'bad spirits'.

'... maybe bad spirits, when people get into trouble, get stressed up, they make bad things happen' (community member) [22].

Related to the concept of 'bad spirits' was the notion of 'payback'. Some Aboriginal and Torres Strait Islanders believed that cancer resulted from a curse placed on them by somebody seeking retribution or because an individual disobeyed laws, traditions or customs. They believed that nothing could be done to alter the outcome.

'So if there has been some recent troubles, that's enough to get them looking for *payback*. It is an evil thing. I've seen people just fade to nothing and die' (health worker) [22].

The sub-theme of fatalism was also illustrated by participants who felt discouraged from talking about cancer because of a perception that talking about it could result in it happening.

'I think talking about it [cancer] can bring it on' (participant not identified) [22].

Participants perceived that maintaining the wholeness of the human body was important.

'Our body was a creation of God that we should not interfere with ... no matter what happen [*sic*]' (patient) [22].

This concept of the sacredness of the body was evident in several of the reviewed articles. One participant discussed how treatment

'... violates the essence of the woman, her inner sacredness of being a woman' (health care worker) [22].

As a result, losing a breast as a treatment for breast cancer was a significant threat to their identity, their womanhood and their roles as mothers and wives.

'Losing a breast is a big thing to cope with, that part of womanhood, having a breast. If you were young and you lost it you couldn't breastfeed, so that is taking a part of your motherhood, a part of nature away from you, and that is a lot to deal with. Then again, your husband is going to look at you stupid because you are only half a woman' (community member) [21].

Theme 2: Cultural influences

Culture may be defined as '...a set of shared and socially transmitted ideas about the world that are passed down from generation to generation' [25]. Among indigenous peoples, these socially transmitted ideas include the value placed on family and kinship responsibilities, beliefs about the relationship to their land or country and long-standing traditional practices [26]. These cultural protocols have strong influences on responses to diagnosis and treatment of health issues [25], and this review found, in particular, that the importance of family and the shame associated with being seen to breach cultural traditions influenced decision-making about cancer treatment.

The importance of relationship with family was seen in the decisions about treatment of cancer made by Aboriginal Australians from rural and remote areas. Members of the extended family feel responsibility for the person requiring treatment, while that person simultaneously feels responsibility to the family group.

'If a person who has cancer has to go away for treatment, it not only affects the person, but the whole family. There are a lot of factors then impacting on that decision to go away to Brisbane for a week of treatment – looking after elderly people in the family, looking after other people in the family with problems' (patient) [21].

A sense of shame was experienced by some Aboriginal and Torres Strait Islanders when they were diagnosed with cancer. These feelings of shame were brought about by the social stigma attached to community perceptions that cancer has been caused by a breach of cultural traditions.

'Some don't want to talk about cancer because of what other people will think. They might think it is a dirty disease or they caught it [cancer] from mucking around, you know not having a clean life. So they don't want to get a bad reputation, they keep it [cervical cancer] to themselves until it's too late' (Aboriginal health worker) [22].

A heightened sense of shame was also apparent when patients believed they had violated gender-based cultural traditions, such as undergoing procedures that threatened physical or spiritual integrity or when expected to

'expose their body to the whiteman's medical gaze or divulge information about sexual practices, which are considered women's private business' [22].

Some cancers, particularly those in private areas such as breast or cervix, were associated with even more intense feelings of shame. There was often a perception in the family and wider community that the woman diagnosed with breast or cervical cancer had been unfaithful in her

marriage. For instance, Prior found in her study that some of the participants would not even go for cancer screening because of concerns that a positive result would suggest to others that she had been 'messing around' [22]. Following this line of thinking, many women avoided seeking treatment for reproductive system cancers.

Theme 3: Communication

Effective communication has been recognised as an important contributor to successful health outcomes. However, in this review, it was noted that many indigenous cancer patients and survivors avoided discussing their illness with health professionals, family and community members. If they did attempt to talk about it, they often found that friends and family were not willing to engage in the conversation. This paper has already identified the belief among some Aboriginal and Torres Strait Islanders that talking about cancer can make it happen. Other reasons identified for the reluctance to talk about cancer included fear and a lack of knowledge.

'People don't like to talk about cancer it makes them feel bad. If someone gets it [cancer] people stay away, they're afraid of it, they might think you can catch it or something, but mostly they don't like to talk about it' (family member) [22].

Women with vulvar cancer experienced fear about the seriousness of their condition and shame associated with disease in intimate areas of their bodies. These feelings contributed to them being

'too scared to even talk to female relatives about their cancer...' [20].

This silence about cancer was also influenced by the belief that cancer is contagious. It was not uncommon for people with cancer to describe being avoided by family and community members, because they believed it was contagious.

'There was one lady ... she actually couldn't sit next to me. She sat across the room from me. She wouldn't talk to me for a long time, because she was scared...' (Aboriginal patient) [17].

The communication style of health professionals was identified as having a negative effect on treatment decision-making. The lack of open and empathetic communication, along with health professionals' lack of understanding or commitment to the establishment of a trusting relationship (or the perception of same by the patient and their family), impacted on the individual's

willingness to seek advice and assistance regarding health concerns.

'Doctor can diagnose, but they don't follow up with it properly. Or they refer you on to someone else and you don't have time to build up a rapport with anyone. You don't know where you are, you're confused, you've got low self-esteem because you're feeling bad about yourself, all this fear comes into it' (family member) [21].

Ineffective communication between health professionals and patients, combined with the unwillingness to talk about cancer, contributed to knowledge deficits about cancer and treatment options. This lack of knowledge meant that Aboriginal and Torres Strait Islanders often did not seek medical advice for symptoms until the cancer was at a later stage, frequently believing they did not need treatment.

'She keeps saying, "I have no more cancer... oh they took it all now..." And I keep saying to her, "Mum, no, it's not true. It's still in your body. Although they took your bubies off, you still got the disease. You got to be careful..."' (family member) [18].

Theme 4: Existing health care systems and structures

Although arguably successful and effective, today's complex and highly technological health care structures and systems can contribute to disempowerment of patients. This review identified that inaccessibility of existing health services and lack of culturally appropriate infrastructure and support influenced cancer treatment decision-making among Indigenous Australians. Patients from rural and remote areas were generally required to attend hospitals in major centres for treatment. This requirement precipitated significant practical and logistical issues such as finding accommodation in the city while undergoing treatment, dealing with unfamiliar transport and settings, as well as the associated financial cost.

'People think "no I don't want to go down because I've got no way of getting there, going to the hospital, or I don't have any family down there", so they choose not to' (family member) [18].

For patients from rural and remote areas, journeys from their community to cancer treatment centres could necessitate travel over hundreds of kilometres, often requiring several days of travel and several changes of transport. This lengthy travel, along with the lack of familiarity with the urban centre, contributed to feelings of disorientation. One participant from a study conducted in Western Australia explained:

'They don't know which end of [the city of] Perth is left, right or centre....like when people come to Perth they say "Just go to the hospital". How do people know where the hospital is ... especially some people who have never left their home town' (patient) [18].

Even once the hospital has been located, the lack of orientation to its environs also contributed to stress, particularly for those with limited literacy skills. It was not easy for patients to find their way around the hospital or to follow the signs to the various departments.

'Unless you can read ... I am lucky I have learned, but some of the elders and some young people who are stressed out and walking around trying to find B block [in the hospital] or whatever, the radiation centre...yeah, it's hard...you can't find the place' (family member) [18].

Fear about leaving the community to receive cancer treatment was exacerbated by separation from family and social networks, resulting in additional stress and feelings of loneliness.

'I think it is scary for an Indigenous person to go down to the city and have no one there supporting them ... sometimes the doctor can speak to them and they would not understand what they had been told ... I mean they will probably really want someone from their family' (patient) [21].

The availability of family support and access to social networks were significant influences on initiation and maintenance of treatment.

'Not to be too far from home or they'll be homesick as well. [to have] friends, family, pets if hospitalised...' (health worker) [22].

When there was a lack of access to Indigenous health workers, Aboriginal and Torres Strait Islanders struggled to talk openly because of the cultural influences and traditions associated with communication.

'She had a support worker but she was white and she didn't want to ring her, didn't want to talk to her. She wanted someone that was from the same culture. There was no-one up here. I tried looking for someone and there was nothing' (participant not identified) [21].

Discussion

This systematic review has identified a set of factors that influence the decision-making by indigenous people with regard to cancer treatment. These factors are the

following: spiritual beliefs about the cause of cancer and the conceptualisation of the body; cultural influences associated with family and community relationship and the shame of a diagnosis of cancer; the nature of communication between indigenous patients, their families and non-indigenous health professionals; and the availability of support services and appropriateness of health infrastructure.

This review demonstrated that, among Aboriginals and Torres Strait Islanders, there is a widely held belief that a diagnosis of cancer means they are going to die [17,21,22]. Such a belief is not restricted to Australia's Indigenous peoples [27] nor to indigenous people only [25,26]. Among Aboriginal and Torres Strait Islanders, however, there is a further belief that there is nothing they can do to change this fact [17,18,20–22]. Cohen [24] identified such fatalism as being higher among minority groups and those with low socio-economic status, as a result of lack of knowledge and lack of access to health services, both of which have been demonstrated in this review to influence cancer treatment decision-making. These beliefs are deeply rooted in Indigenous spirituality and are reinforced by the relatively high mortality rate for cancer among Indigenous people [27,28]. It has been found that spirituality is a critical factor in the health and well-being of cancer patients and mostly exerts positive effect on their quality of life and coping with illnesses in the general population. However, findings of this review suggest spirituality may exert a negative influence among indigenous people with cancer.

Cancer treatments that involve some sort of disfigurement, such as breast cancer [21,22], as well as those involving removal of internal organs [26], challenge indigenous people's spirituality attached to the body. In the indigenous worldview, the body is inseparable from the self, which is embedded within connections to family, community and land [29]. Hence, removal of a part of the body is believed to diminish not just oneself, but the whole [21,22], and this belief in maintaining the wholeness of the body may override the need for cancer treatment. This systematic review has identified that this holistic worldview strongly influences the decision-making process for accepting cancer diagnosis and treatment. Health service providers must acknowledge, consider and respect such worldviews to be able to truly improve the cancer outcomes for indigenous patients.

As has been widely reported, key domains affecting indigenous social and emotional well-being include the following: connection to body, mind and emotions; family and kin; community; culture; land; and spirituality [29]. Indigenous spiritual beliefs resonate with the notion of connectedness [29], and connection to family, community and country is the strong tie that nurtures and sustains Indigenous people's health and well-being [26]. The traditional cultural value and commitment placed on family ties and responsibilities may be stronger or more

important than taking up cancer treatment, particularly for patients from rural and remote locations who must by necessity leave their home and family to undergo treatments that are mostly city-based [18,21,22].

The association of cancer with shame and embarrassment in Indigenous cultures is linked to the breaching of traditional cultural values, norms and rituals, which brings 'shame' not only to the individual but also to their family and community [26]. Traditional beliefs about cancer being a 'dirty' and 'Whiteman's disease' may stop indigenous people talking about the disease for fear of cultural backlash [20,22]. Communicating about cancer within family and community was also restrained by a belief that cancer is contagious [17,22], while communication with health professionals about cancer was limited by inappropriate language and lack of trust [20,21]. It is widely reported in the literature that effective communication between health professionals and patients positively impacts on patient decision-making to access treatment services, reducing their anxiety, understanding of treatment risks and prognosis, patient satisfaction and the effective delivery of health care [17,30,31]. The culturally imbued reluctance among some Aboriginal and Torres Strait Islanders to talk about cancer subsequently influences their decisions to seek advice regarding symptoms [18,20,22]. It also limits the support available when receiving treatment [18] and possibly reduces the likelihood that they will complete treatment [18,21].

Notwithstanding the issues associated with communication, indigenous cancer patients consider the support of family, access to social networks and availability of culturally appropriate health care to be important factors in treatment decision-making [18,21,22]. In Australia, these values are complicated by the fact that a large proportion of Aboriginal and Torres Strait Islanders live in rural or remote areas. This situation is similar for indigenous people in other countries such as New Zealand, Canada and the USA, which share similar historical legacies for their indigenous populations [7,27]. It has been widely reported that remoteness poses particular health service challenges to improving health outcomes [32,33]. The distance, lack of transport, lack of availability of physicians and health infrastructure are major obstacles to accessing appropriate primary, specialist and follow-up health care for people with cancer living in rural and remote areas [34]. This review identified the significant influence on cancer treatment decision-making of rural and remote Aboriginal and Torres Strait Islanders if they are required to separate from family, community and country in order to receive treatment [18,21,22]. This separation was exacerbated by the unfamiliarity of the urban environment and the inflexibility of the hospital culture [18,22]. We have earlier noted the central function of connection to family, community and country in indigenous people's views of health and well-being. This

review has highlighted the importance given to the maintenance of this connection in their decision-making regarding cancer treatment.

Limitations of the review

Despite a thorough search of databases of academic literature, only five articles met the inclusion criteria; the included articles were set in the Australian context, and thus, the findings of this review may only have relevance to Aboriginal and Torres Strait Islander peoples. The scope of the review may have been limited by the selection of search terms, as terms for each and every indigenous population group around the world were not specifically included, as it was thought that use of the general terms 'indigenous' and 'aboriginal' would capture all such peoples. In choosing not to search the grey literature, we may have missed some articles or dissertations; however, it is acknowledged that cancer diagnosis, screening and treatment in indigenous peoples have only recently been investigated [27]. Lastly, the fact that all included studies were methodologically qualitative may have been influenced by the objective of this systematic review, as the qualitative approach is acknowledged to be useful for understanding the perspectives of people experiencing health issues [19]. All five primary research studies were considered of high methodological quality, as determined by the CASP criteria [15].

Recommendations for practice

The provision of culturally appropriate cancer care requires health professionals to acknowledge beliefs of indigenous people about the causes and effects of cancer, to accept these beliefs as valid for the people who hold them and to apply models for decision-making in practice that utilise this approach. Culturally appropriate health care requires health professionals to be well trained in the use of interpersonal skills and to apply these skills to the development of therapeutic relationships in which indigenous people with cancer are engaged and empowered. This requires accommodating indigenous people's beliefs within the health system so that indigenous patients and families are supported in a culturally appropriate manner during the cancer treatment journey.

Indigenous people's cultural beliefs also affect how and to whom they talk about cancer, which influences participation in cancer treatment and support for those who have cancer. Health professionals at all levels need to be cognisant of this in their work with indigenous people and learn to use language – both verbal and non-verbal – which is respectful of cultural traditions and practices if they wish to promote consistent and effective engagement with treatment services. In an effort to overcome myths and misconceptions about cancer and cancer treatment

among both indigenous cancer patients and the health professionals, indigenous people must participate fully in the design and implementation of health education programmes focusing on interpersonal skills, cultural sensitivity and cultural safety.

While all cultures value family and kinship ties, the spiritual life and existential meaning of indigenous cultures are dependent on these ties. Connection is integral to the indigenous expression and experience of life [29]. It is essential for cancer treatment plans for indigenous people to recognise this connection because many indigenous patients will prioritise their connection to family, community and land over any benefits to be gained from successful cancer treatment.

The pivotal sense of connection is particularly stressed for many indigenous people with cancer when geographic and health system factors prevent cancer treatment being delivered close to home. Strategies do exist that can support people in remote areas to receive effective health care, and these should be more effectively supported and resourced. The provision of primary health care in rural and remote areas is essential. Community-based health positions (in the form of lay health advisor or community health worker) can be employed to enhance communication and support linkages between the patients and the health services. The option of using tele-medicine could be further explored and trialled as it has been found that effective communication and a satisfactory health professional–patient relationship are possible through this model of care, and several of the infrastructural issues in rural settings can also be well addressed [35].

Recommendations for research

Considerable international research is required to address the gap in research investigating cancer treatment decision-making among indigenous peoples, which has been identified by this review. While health professionals, researchers and policymakers are cognisant of the importance of culturally appropriate cancer care, research investigating health professionals' knowledge of and attitudes

towards indigenous people's spirituality needs investigation if culturally appropriate care is truly to be implemented. Greater understanding of the impact of health professionals' communication with indigenous people is also needed, along with research investigating 'best practice' in communication that facilitates acceptance and completion of cancer treatments by indigenous peoples.

Conclusion

The objective of this systematic review was to identify the factors known to influence the cancer treatment decision-making of indigenous peoples. We have shown that there are multiple complex and inter-related factors affecting cancer treatment decision-making among indigenous peoples, most of which arise from their spiritual and cultural worldview. As demonstrated by the dearth of international literature, the topic is under-researched. Thus, much needs to be done in the practice and research domains to develop and implement culturally appropriate, practical, context-specific, hands-on programmes and services that promote informed cancer treatment decision-making among indigenous peoples. Findings from this review indicate that such programmes and services should foreground traditional beliefs about the causes and effects of cancer and the priority placed on connection to family, community and country/land by Indigenous cancer patients and their families.

Conflict of interest

To avoid any conflict of interest, SS did not contribute to the article selection processes or participate in the data analysis and synthesis. The authors declare that there are no other conflicts of interest.

Acknowledgements

Thank you to Geoff Lattimore, medical librarian, for his assistance with the literature search.

References

Note: Papers marked with the asterisk (*) were included in the systematic review.

- World Health Organisation (WHO). Health of indigenous peoples. 2007 Accessed 28 July 2014 from <http://www.who.int/mediacentre/factsheets/fs326/en/>
- World Health Organisation (WHO). Indigenous Health – Australia, Canada, Aotearoa New Zealand and the United States – Laying claim to a future that embraces health for us all. 2010. Accessed 28 July 2014 from <http://www.who.int/healthsystems/topics/financing/healthreport/IHNo33.pdf>
- International Work Group for Indigenous Affairs 2010. The indigenous world. Accessed 28 July 2014 from http://www.iwgia.org/iwgia_files_publications_files/0001_I_2010_EB.pdf
- National Aboriginal Community Controlled Health Organisation. Close the gap campaign. 2014. Accessed 28 July 2014 from <http://www.naccho.org.au/aboriginal-health/close-the-gap-campaign/>
- Australian Institute of Health and Welfare. Australia's health 2014. Australia's health series no. 14. Cat. no. AUS 178. Canberra: AIHW.
- Valery P, Coory M, Stirling J, Green A. Cancer diagnosis, treatment, and survival in Indigenous and non-Indigenous Australians: a matched cohort study. *Lancet*. 2006;**367**:1842–1848.
- Canales MK, Weiner D, Samos M, Wampler NS. Multi-generational perspectives on health, cancer, and biomedicine: Northeastern Native American perspectives shaped by mistrust. *J Health Care Poor Underserved* 2011;**22**(3):894–911. DOI:10.1353/hpu.2011.0096.
- Guadagnolo BA, Cina K, Helbig P, et al. Medical mistrust and less satisfaction with health care among Native Americans presenting for cancer

- treatment. *J Health Care Poor Underserved* 2009;**20**(1):210–226. DOI:10.1353/hpu.0.0108.
9. Hughes CK. Factors associated with health-seeking behaviors of Native Hawaiian men. *Pac Health Dialog* 2004;**11**(2):176–182.
 10. McDonald JT, Trenholm R. Cancer-related health behaviours and health service use among Inuit and other residents of Canada's north. *Soc Sci Med* 2010;**70**(9):1396–1403. DOI:10.1016/j.socscimed.2010.01.008.
 11. Spector RE. Cultural Diversity in Health and Illness, New York, NY: Prentice Hall Health, 2000.
 12. Hill S, Sarfati D, Blakely T, Robson B, Purdie G, Chen J.... Kawachi I. Survival disparities in Indigenous and non-Indigenous New Zealanders with colon cancer: the role of patient co-morbidity, treatment and health service factors. *J Epidemiol Community Health*. 2010;**64**:117–123. DOI: 10.1136/jech.2008.083816
 13. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA). The PRISMA statement. Retrieved on 26 April 2014 from <http://www.prisma-statement.org/statement.htm>
 14. Gaston CM, Mitchell G. Information giving and decision-making in patients with advanced cancer: a systematic review. *Soc Sci Med* 2005;**61**(10):2252–2264.
 15. Critical Appraisal Skills Programme (CASP). Qualitative research checklist. Accessed 16 May 2014 from http://media.wix.com/ugd/dded87_951541699e9edc71ce66c9bac4734-c69.pdf
 16. Singh J. Critical appraisal skills programme. *J Pharm Pharmacotherap* 2013;**4**(1):76–77. DOI:10.4103/0976-500X.107697.
 17. * Shahid S, Finn L, Bessarab D, Thompson SC. Understanding, beliefs and perspectives of Aboriginal people in Western Australia about cancer and its impact on access to cancer services. *BMC Health Serv Res* 2009;**9**(132). DOI:10.1186/1472-6963-9-132.
 18. * Shahid S, Finn L, Bessarab D, Thompson SC. 'Nowhere to room ... nobody told them': logistical and cultural impediments to Aboriginal peoples' participation in cancer treatment. *Aust Health Rev* 2011;**35**(2):235–241. DOI:10.1071/AH09835.
 19. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodology* 2008;**8**. DOI:10.1186/1471-2288-8-45.
 20. * McGrath P, Rawson N. Key factors impacting on diagnosis and treatment for vulvar cancer for Indigenous women: findings from Australia. *Support Care Cancer* 2013; **21**(10): 2769–2775. DOI: 10.1007/s00520-013-1859-7. doi: 10.1007/s00520-013-1859-7
 21. * McMichael C, Kirk M, Manderson L, Hoban E, Potts H. Indigenous women's perceptions of breast cancer diagnosis and treatment in Queensland. *Aust N Z J Public Health* 2000;**24**(5):515–519.
 22. * Prior D. The meaning of cancer for Australian Aboriginal women; changing the focus of cancer nursing. *Eur J Oncol Nurs* 2009;**13**(4):280–286. DOI:10.1016/j.ejon.2009.02.005.
 23. De Jager ME, Garssen B, van den Berg M, Tuytel G. Measuring spirituality as a universal human experience: development of the Spiritual Attitude and Involvement List (SAIL). *J Psychosoc Oncol*. 2012;**30**:141–167. DOI:10.1080/07347332.2011.651258.
 24. Cohen, M. (2013). Cancer fatalism: attitudes toward screening and care. In B. Carr & J. Steel (eds). *Psychological Aspects of Cancer*. 2013. Springer, New York.
 25. Daher M. Cultural beliefs and values in cancer patients. *Ann Oncol*. 2012;**23**(supplement 3):66–69. DOI: 10.1093/annonc/mds091
 26. McGrath P, Holewa H, Ogilvie K, Rayner R, Patton M. Insights on Aboriginal peoples' views on cancer in Australia. *Contemporary Nurse* 2006;**22**(2):240–254.
 27. Shahid S, Thompson S. An overview of cancer and beliefs about the disease in Indigenous people of Australia, Canada, New Zealand and the US. *Aust N Z J Public Health* 2009;**33**(2):109–118. DOI:10.1111/j.1753-6405.2009.00355.x.
 28. Condon J, Zhang X, Baade P, et al. Cancer survival for Aboriginal and Torres Strait Islander Australians: a national study of survival rates and excess mortality. *Popul Health Metr* 2014;**12**(1). DOI:10.1186/1478-7954-12-1.
 29. Gee G, Dudgeon P, Schultz C, Hart A, Kelly K. Aboriginal and Torres Strait Islander social and emotional wellbeing. In P Dudgeon, H Milroy & R Walker (Eds.) *Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice* 2014 (2nd ed.). Telethon Kids Institute, Kulunga Aboriginal Research Development Unit, Department of the Prime Minister and Cabinet (Australia). Accessed 14 November 2014 from <http://aboriginal.telethonkids.org.au/media/699863/Working-Together-Book.pdf>
 30. Fong J, Longnecker N. Doctor–patient communication: a review. *Ochsner J* 2010;**10**(1): 38–43.
 31. Travaline JM, Ruchinkas R, D'Alonzo GE. Patient–physician communication: why and how. *J Am Osteopath Assoc* 2005;**105**(1): 13–18.
 32. Humphreys J, Wakerman J. Primary health care in rural and remote Australia: achieving equity of access and outcomes through national reform. A discussion paper. 2002. Accessed 14 November 2014 from [http://www.health.gov.au/internet/nhhrc/publishing.nsf/content/16f7a93d8f578db4ca2574d7001830e9/\\$file/primary%20health%20care%20in%20rural%20and%20remote%20australia%20-%20achieving%20equity%20of%20access%20and%20outcomes%20through%20national%20reform%20\(j%20humph.pdf](http://www.health.gov.au/internet/nhhrc/publishing.nsf/content/16f7a93d8f578db4ca2574d7001830e9/$file/primary%20health%20care%20in%20rural%20and%20remote%20australia%20-%20achieving%20equity%20of%20access%20and%20outcomes%20through%20national%20reform%20(j%20humph.pdf)
 33. Australian Institute of Health and Welfare (AIHW). Rural, regional and remote health—indicators of health, 2005; AIHW Cat. No. PHE 59. Canberra Australia: AIHW. Accessed 28 November 2014 from <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=6442459626>
 34. Lowenthal R, Grogan P, Kerrins E. Reducing the impact of cancer in Indigenous communities: ways forward. *Med J Aust* 2005;**182**(3): 105–106.
 35. Sabesan S, Larkins S, Evans R, et al. Telemedicine for rural cancer care in North Queensland: bringing cancer care home. *Aust J Rural Health* 2012;**20**(5):259–264. DOI:10.1111/j.1440-1584.2012.01299.x.