

9-15-2011

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Citation of this paper:

Schaik, K. D. and Thompson, S. C., "Indigenous beliefs about biomedical and bush medicine treatment efficacy for indigenous cancer patients: a review of the literature" (2011). *Aboriginal Policy Research Consortium International (APRCi)*. 379.
<https://ir.lib.uwo.ca/aprci/379>



Indigenous beliefs about biomedical and bush medicine treatment efficacy for indigenous cancer patients: a review of the literature

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Key words

Indigenous, cancer, treatment, bush medicine.

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Received 2 September 2010; accepted 15 September 2011.

doi:10.1111/j.1445-5994.2011.02598.x

Abstract

Background: Australia's Indigenous people suffer from higher cancer mortality than non-Indigenous Australians, a discrepancy partly caused by differences in beliefs about treatment efficacy between Indigenous patients and their non-Indigenous healthcare providers. This paper critically reviews the literature associated with Indigenous beliefs about cancer treatment, both 'bush medicine' and biomedical, in order to provide recommendations to healthcare providers about accommodating Indigenous beliefs when treating cancer.

Methods: A search was undertaken of peer-reviewed journal papers using electronic databases and citation snowballing. Papers were selected for inclusion based upon relevance to themes that addressed the research questions.

Results: Literature suggests that Indigenous beliefs about treatment efficacy for cancer involve five themes: (i) concerns about the toxicity of treatment; (ii) disconnect with the physician; (iii) fears about absence from home during treatment; (iv) different beliefs about disease aetiology; (v) biomedical cancer treatments failing to address holistic health.

Conclusions: Although some information is known about Indigenous Australian healing beliefs and practices associated with cancer treatment, few studies have addressed ways in which Indigenous and biomedical approaches to cancer treatment might be integrated. Some recent work has examined the role of belief in cancer treatment, specifically bush medicine, but more research is required.

Introduction

Indigenous Australians suffer from higher cancer morbidity and mortality than non-Indigenous Australians.¹⁻³ They are less likely than non-Indigenous people to use preventive and screening services, and, when diagnosed, to receive treatments such as surgery, chemotherapy and radiotherapy.⁴ There are many reasons for this discrepancy, including socioeconomic and educational factors, language barriers, and lack of healthcare provider familiarity with cultural practices and transportation issues.⁵

In the last decade, several studies have identified another, less obvious reason for discrepancies in cancer outcomes: differences of explanatory models of illness and belief systems.^{6,7} Such research has revealed that in some cases, Indigenous peoples' unwillingness to receive treatment for cancer is related to their beliefs about the disease and its treatment: for example, that cancer is incurable, that biomedical treatment is excessively toxic or that biomedical treatment may not be effective if the cancer occurred as a form of payback.⁸⁻¹⁰ Indigenous patients may be more willing to receive biomedical treatment if their healthcare providers paid greater attention to Indigenous beliefs about cancer. A healthcare provider's willingness to incorporate elements of Indigenous treatments and explanatory models into a treatment plan has led to better outcomes for Indigenous cancer patients.^{6,7}

This paper reviews the literature available on Indigenous beliefs in treatment efficacy to distil what can be learned from these combined sources, with the goal of

Work was performed at the Combined Universities Centre for Rural Health.

Funding: Financial support for the project was provided by Harvard University Medical School, Boston, Massachusetts, United States.

Conflict of interest: None.

guiding healthcare providers' consideration of beliefs about treatment in developing cancer treatment plans for Indigenous Australians. Furthermore, the review seeks to identify gaps in knowledge and areas for future research. Characterisation of explanatory models and belief systems and application of such knowledge to medical practice are essential to reducing morbidity and mortality among Indigenous people with cancer.

Methods – search strategy and approach

This review draws upon the existing literature to present a summary of what is known about Indigenous views of bush medicine and biomedical treatments for cancer, and to provide recommendations for healthcare providers about accommodating both treatment types with the goal of reducing cancer mortality among Indigenous Australians.

We undertook a search of the literature for material relevant to the following research questions:

- What is known about Indigenous Australians' views of biomedical cancer treatment?
- What is known about Indigenous Australians' views of bush medicine treatments for cancer?
- What success, if any, has there been in combining these two approaches to treat cancer in Indigenous Australian patients?
- What recommendations might be presented to Australian healthcare providers to facilitate their integration of both treatment methods, with the goal of improving outcomes and decreasing morbidity and mortality among Indigenous Australian cancer patients?

The search process was similar to a systematic review in methodically utilising electronic databases, and it also incorporated the critical interpretive synthesis approach in that themes emerged as the literature was searched. This dual method was more appropriate given the relative paucity of literature relevant to the topic at the time of writing.

Peer reviewed journal papers were selected following a search of electronic databases including Proquest, Science Direct, Google Scholar, PubMed, Medline, Academic Search Premier (EBSCO), PsychINFO, Informit and ISI Web of Knowledge, and citation snowballing was undertaken. Key search terms used included combinations of the following: Indigenous, Aboriginal, cancer, belief, bush medicine, treatment. Publications were considered for inclusion if they addressed at least one of the research questions mentioned earlier. Papers that did not refer to Indigenous or Aboriginal or Torres Strait Islander people of Australia were excluded.

Results

Available literature revealed five themes related to Indigenous people's beliefs about treatments and treatment efficacy for cancer:

- 1 Concerns about the toxicity, side-effects and potential disfigurement of treatment.
- 2 A feeling of disconnect with the physician.
- 3 Fears about distance from home and family when treatment requires relocation to a hospital far from home.
- 4 Beliefs about disease aetiology that differ from those presented by the Western biomedical model.
- 5 Failure of biomedical treatments to address holistic health, in contrast to bush medicine treatments that do address holistic health.

Concerns about the toxicity, side-effects and potential disfigurement from treatment

The outcomes of many qualitative studies reveal Indigenous concerns about the toxicity, side-effects, and potential disfigurement of cancer treatment, and these beliefs underpin to some extent quantitative hospital admission data showing that Indigenous people are less likely to receive aggressive cancer therapies. Condon *et al.* completed a retrospective cohort study of 1197 Indigenous and non-Indigenous people in the Northern Territory diagnosed with colon, rectum, lung and breast cancer, as well as with non-Hodgkin lymphoma, between 1991 and 2000.⁴ Surgery was recommended for 70% of non-Indigenous patients and 61% of Indigenous patients; chemotherapy for 34 and 35%, and radiotherapy for 34 and 36% of non-Indigenous and Indigenous patients respectively. Of the patients for whom each procedure was recommended, for non-Indigenous and Indigenous patients, respectively, 99% and 90% chose surgery, 93 and 87% chose chemotherapy, and 94 and 84% chose radiotherapy. Finally, of the patients who chose the procedures, for non-Indigenous and Indigenous patients, respectively, 99 and 100% completed surgery, 83 and 68% completed chemotherapy, and 96 and 88% completed radiotherapy. This demonstrates a difference in treatment for Indigenous people, in providers' treatment recommendations, and in patients' consent to and completion of treatment.⁴

Qualitative studies have attempted to characterise the reasons for these discrepancies. Prior indicates that interviews, focus groups, and community observation in a remote community in Queensland revealed 'a prevailing belief among Indigenous women that cancer was a "deadly disease" and that treatment was mostly futile'.⁸ Moreover, women 'dreaded the prospect of cancer

treatment especially if it involved surgery'.⁸ Mastectomies were especially anxiety-provoking for Indigenous women 'because the breast was a vital part of their "womaness" and could threaten relationships with their husbands or partners'.⁸ McMichael records that some women felt that loss of a breast signified an inability to provide life and nutrition for children, an essential aspect of womanhood.⁹ The paper by Satherley featuring the work of Michelle Torrens, an Indigenous ovarian cancer survivor who wrote a book about her experiences, suggests that fear of loss of hair, another important symbol of womanhood, is also a treatment deterrent: 'When they mentioned giving me chemotherapy... I seriously considered not having it and just going home. To me, like to most of my friends, the word has very scary connotations. You think you are going to get even sicker and that all of your hair will fall out and never grow back. For us Indigenous women, our beauty is our hair. It is almost sacred and I didn't want to lose it'.¹¹

In addition to the loss of physical symbols of womanhood and one's place within the community, the nausea and sickness associated with chemotherapy were concerning for Indigenous patients. McMichael quotes a woman who reported that her 'aunt had chemotherapy for breast cancer, but I don't know how well it treated it. She had it a couple of times but then stopped it. It made her sick. She didn't feel that it was doing her any good'.⁹ McMichael's work showed that among women with breast cancer, pre-existing belief in efficacy can be diminished by the negative side-effects of the biomedical treatment, which 'does not fit with the women's view of health as feeling well and being able to care for one's children (or grandchildren)'.⁹

Shahid, interviewing Indigenous cancer survivors, cancer patients and close relatives of cancer patients, found that some patients used traditional healers and bush medicine, in part to help cope with the toxicity of radiation and chemotherapy. One respondent described an acquaintance who had forsaken biomedical treatments for bush medicine: 'She looked better when she took the bush medicine'.⁷ Some Indigenous respondents said they would be willing to try bush medicine if Western medicine failed, and others reported using bush medicine concurrently with chemotherapy when available, often without telling their doctors because the providers never inquired about bush medicine use.⁷

A feeling of disconnect with the physician

Patient-physician relationships can be prone to miscommunication regardless of the patient's cultural background, and such miscommunication is especially

an issue for Indigenous patients: there is no Indigenous word for cancer.^{10,12} Physician communication and patient understanding of treatments – their side-effects, duration and recovery time – is often difficult to achieve for both linguistic and cultural reasons.¹³ The general dangers of miscommunication in healthcare settings, described in the following, are especially applicable to Indigenous cancer patients: 'taking prescribed drugs without a full knowledge of their purpose or side-effects, being admitted to hospital unaware of the type of medical treatment the patient was to receive, receiving medical treatment without consent, being mistaken for other hospital patients and receiving inappropriate treatment, being returned home with a serious condition, patients undergoing treatment at odds with [patients'] cultural beliefs'.¹³ These consequences of miscommunication are profound for cancer patients, who often have complicated treatment plans and are immunocompromised.

There are many anecdotes of the dangers of physician-patient miscommunication with Indigenous cancer patients, some of which have been published:¹⁴ one patient with throat cancer had his larynx removed, unaware that his tracheostomy and gastrostomy tubes would be permanent and would require cleaning. His wife thought that the operation would cure him, and his inability or unwillingness to clean the tubes led to his rehospitalisation, a few weeks after which he passed away. The paper containing this story provides similar descriptions of cultural collision and misunderstanding with potentially avoidable consequences, had treatment been explained more fully to the patients.¹⁴

Such miscommunication between Indigenous patients and their physicians compounds a pre-existing lack of trust in the Western medical establishment.¹⁵ An assessment of patients who chose to take their own leave from hospital in Alice Springs revealed that one individual attributed leaving to having seen a nurse hit a child.¹⁶ Further questioning indicated that the incident had happened years prior, but that the event remained in the patient's mind, reinforcing collective cultural memory: such concerns continue to influence Indigenous attitudes towards the hospital in a negative way, discouraging participation in treatment.

Related to miscommunication and lack of trust in the Western medical establishment is the issue of 'unrealistic expectations' of cancer treatment.^{9,10,12} The lack of effective communication can lead patients to believe that cancer treatments will necessarily lead to a cure. If such an outcome does not result, the potential exists for further distrust of the Western medical establishment and biomedical treatments by Indigenous community members, who often see patients leave their communities for treatment only to die while in hospital.⁹

Fears about distance from home and family when treatment requires relocation to a hospital far from home

Although the concern of Indigenous patients that treatment for cancer requires travel and being distant from home and family is not directly related to views of treatment efficacy, such views remain important reasons for foregoing biomedical treatment, and therefore merit discussion here.

Cancer treatment usually occurs at larger medical centres that may be hundreds of kilometres away from where a patient lives, in an environment that is culturally distant from home.^{5,8,9,14,15} Cancer diagnosis and treatment are stressful times,⁹ and the stress is worsened by the lack of a social support network when the patient is in hospital for treatment, and by considerations of logistics and costs.¹⁷ Moreover, travelling to hospital and remaining there for treatment means that patients cannot fulfil community social obligations,^{8,9} prompting some patients to decline any hospital-based treatment so they can remain at home.⁸ Many patients taking their own leave from Alice Springs Hospital, for example did so because of distance from home and family.¹⁶ Additionally, cancer itself can be isolating, as some Indigenous patients and their families believe that cancer is contagious and will shun contact with the affected person.^{6,8,9,12} The feeling of emotional distance and isolation from one's community, which might follow a cancer diagnosis, can be compounded by the physical distance imposed by having to receive treatment at hospitals away from home and family.

Beliefs about disease aetiology that differ from those presented by the Western biomedical model

Among some Indigenous people there is a perception that cancer is a 'white man's disease', brought to the continent by Europeans, and that it therefore requires 'white man's medicine' and is especially toxic to Indigenous people.^{8,10} This perception of cancer as a European malady links it to other diseases brought to the continent by the first European settlers, such as gonorrhoea and syphilis – diseases that have a social stigma and induce feelings of shame in those who contract them.⁷ Moreover, cancer can be considered to have been brought on by sorcery as a form of payback,^{6,7,12} and Indigenous patients with cancer can experience shame in the face of a cancer diagnosis.⁶⁻⁸

These perceptions of cancer aetiology affect Indigenous peoples' perceptions of how cancer should be treated. While living in a Warlpiri community, Saethre investigated perceptions of disease and treatment, focusing on

the types of treatment sought for particular illnesses.¹⁸ Although the patient stories provided do not include the experiences of cancer, the data are useful in that they show a tendency to seek Western medications such as paracetamol and antibiotics when they are available. Bush medicine was used but could often be difficult to obtain.^{18,19} Urban Indigenous respondents have also indicated that though they might like to use bush medicine, they cannot owing to an inability to procure it in the urban environment.⁷ This suggests that although Western medicines might be considered useful for illnesses perceived to be 'white man's diseases', traditional healers are still sought: this is particularly the case if the reason for the disease is believed to be a form of payback. Some believe that cancer affects only Indigenous people,¹⁰ and one respondent in Saethre's study indicated that a disease that affects only Indigenous people needed to be cured by a traditional healer: 'Those doctors, they don't understand Indigenous sickness. They do X-rays but they still can't see that bone inside'.¹⁸

The literature reveals different and sometimes conflicting views about the effects of cancer on Indigenous patients, though a common theme is the view that cancer did not exist prior to the arrival of European settlers, and that its status as a disease brought by Europeans affects how it should be treated by healers, both traditional and biomedical. Regardless, it is clear that colonial history has shaped perceptions of disease aetiology and treatment efficacy, both biomedical and Indigenous, for specific diseases in Indigenous patients.

Failure of biomedical treatments to address holistic health, in contrast to bush medicine treatments that do address holistic health

As discussed in the work of Boulton-Lewis, which describes beliefs of Indigenous health sciences students, health is defined as 'wellbeing', affected by lifestyle choices and relationships, and 'involves balanced holistic dimensions, including 'physical, mental, spiritual and in some cases social and environmental aspects'.²⁰ Illness was perceived as 'imbalance involving holistic dimensions including physical, spiritual, social and environmental'. Some students responded that illness could be induced by interaction with evil or unhappy spirits. In contrast, the Western perception of illness, particularly cancer, is one of 'biomedical reductionism'.^{10,21} Miscommunication about the process of cancer treatment and unwillingness or inability to adhere to treatment programmes can often be traced back to these two very different views of health, illness, and treatment.

Some Indigenous cancer patients consider biomedical treatment inadequate, especially because (as described

earlier) side-effects make them feel worse than they did prior to treatment. Bush medicine is perceived as addressing holistic health, 'often signifying a re-connection to land, ancestral and spiritual roots that enhanced the person's overall wellbeing'.⁶ As one respondent said about bush medicine: 'There is something in it . . . that is good for your insides, just as a cleanser. Makes all your body organs healthy and strong, it gets rid of all your internal stress'.⁶ The view of bush medicine as a stress reliever fits with a view of cancer as stress-related, an effect of the upheavals and social changes associated with European colonisation.⁷ Bush medicine is believed to relieve stress and to act as a cancer therapy that simultaneously prevents, treats and palliates (for terminal patients).⁷

In some cases, Indigenous patients seek Western medical care and the skills of a traditional healer, or understand the scientific aetiology of a disease in the context of traditional Indigenous belief systems.¹⁸ This allows for the combination of viewpoints, treatments and perspectives but often occurs in an uncoordinated way, with inadequate treatment for Indigenous patients and frustration for healthcare providers. A more effective and efficient way to treat Indigenous patients is to recognise at the outset the importance of holistic healing and to incorporate it into the treatment programme. This is discussed in further detail below.

Success in combining treatment approaches?

Literature detailing methods for combining biomedical and traditional healers or biomedical and bush medicine treatment is nearly non-existent. There is evidence that Indigenous cancer patients and survivors, as well as the family members of individuals with cancer, are willing to use both treatment approaches.^{6,7}

Saethre provides a first-hand anthropological account of two Indigenous people in a Warlpiri community who sought both biomedical and bush medical treatments for their illnesses.¹⁸ Saethre makes the distinction between physical illnesses and spiritual illnesses, the former of which can be treated with Western medicines or bush medicines, the latter of which, sometimes caused by sorcery, require the assistance of an ngangkari healer. Both approaches may be pursued concurrently when an illness – such as cancer – is presented to a Western physician while also believed to be caused by sorcery.^{8,10,22}

Saethre discusses the practice of 'two way' medicine in which 'illness management continues to occur in the clinic, but patients . . . have the choice of consulting nurses, Indigenous Health Workers, or Indigenous healers and being prescribed pharmaceuticals or bush

medicines'. Through describing the medical histories of two community members, Saethre illustrates how Indigenous people adapt the two systems to suit their needs, such as using biomedical drugs (antibiotics and paracetamol) concurrently with ngangkari consultation, or attributing severe illnesses treated in Western hospitals to spiritual causes. Ultimately, Saethre reports how the 'two way' system fails to recognise that this overlap occurs and argues that 'while local conceptions of health do influence how illness is conceived and treated, they should not be automatically reduced to a single or rigid Indigenous system that is contrasted with biomedicine'.¹⁸ Since many Indigenous people are willing to seek biomedical treatment, an approach that seeks to separate 'bush medicine' and 'biomedicine' with regard to patient care is likely to be ineffective for many Indigenous people.^{4,6,17,19,20} Rather, effective treatment needs to integrate both approaches, and to recognise that Indigenous patients can and do combine their perceptions of and treatments for illnesses, including cancer.

Conclusion

The available research regarding Indigenous Australians' beliefs about treatment efficacy for cancer reveals that concerns about biomedical treatment side-effects, long-distance travel to hospitals, cultural distance between patient and provider, differences in belief about disease aetiology, and the inadequacies of biomedical treatment with regard to holistic healing influence Indigenous cancer patients' willingness to undertake and to complete biomedical therapy for cancer. The literature suggests that Indigenous cancer patients generally view biomedical treatment as effective in treating cancer, a 'white man's disease' for which 'white man's medicine' can be effective.^{8,10} However, it is often difficult to identify the extent to which Indigenous patients are truly 'informed' about biomedical cancer treatment, its side-effects, and its efficacy, as evidenced by well-described problems with communication between health providers and Indigenous patients,^{6,14,23} the actions of patients who begin treatment and then cease because of side-effects and toxicity, as well as by the perception among some that treatment is tantamount to a cure.¹²

Few data have been collected about beliefs in efficacy of bush medicine when used specifically for cancer, though the work of Shahid suggests that belief in efficacy is important.⁷ Only limited conclusions can be drawn about the use of bush medicine for cancer, as little research has been completed in this area. Indigenous patients are also generally not forthcoming in sharing information about bush medicine, possibly fearing that their non-Indigenous providers will discourage them

from taking it or otherwise induce feelings of shame.^{6,7} Moreover, research suggests that patients might be concerned that sharing information about bush medicine will reduce its efficacy.^{6,7} It appears even more difficult to explore the perspectives of traditional healers, given their concerns of being custodians of traditional knowledge that could be exploited by non-Indigenous people.^{6,7}

This review of beliefs about treatment efficacy reveals that more research is needed regarding Indigenous expectations about side-effects and treatment toxicity and the difficulties associated with patient-physician communication. More research in these areas might contribute to Indigenous patients being encouraged to participate in cancer screening where the consequences of finding an abnormality must be a consideration. Reducing the fear and mystery associated with treatment means that if cancer were discovered, patients may be more willing to complete a full treatment programme. A thorough understanding of beliefs and anxieties about treatment would allow healthcare workers to address these concerns early, facilitating the promotion of participation in screening programmes. Australia could also learn from other developed countries such as Canada, New Zealand and the United States in their Indigenous-led approaches that have been adopted in order to improve treatment engagement and outcomes.^{24–27}

Indigenous Australians are diverse and heterogeneous, so treatment needs to be personalised to individual beliefs and concerns. However, health providers showing that they care enough to know about the beliefs of Indigenous people that fall outside of the standard Western model may also help Indigenous patients to feel that they are receiving sincere, culturally sensitive care. The feeling of 'being treated as a number' and the absence of patient-physician relationship are recurring themes in research exploring Indigenous peoples' views of healthcare services.⁶ Identification of the broad range of thinking in relation to healing, and specific beliefs about bush medicine – how it works, when it is used and what makes it appealing – could promote among healthcare providers greater willingness to use a more holistic healing model when treating Indigenous patients. If beliefs about and utilisation of bush medicine for cancer were more fully characterised, treatment plans that combine both biomedical and bush medicine treatments could be developed, potentially leading to better psychosocial outcomes as well as increased treatment adherence and patient satisfaction, and decreased morbidity and mortality. Moreover, as complementary medicine usage is so common in the general community, changes in approach – catalysed by the need to improve Indigenous cancer outcomes – are likely to have broader applicability in the multicultural societies of our modern world.

Guidelines for healthcare providers

The following are some underlying guiding principles for hospital Cancer Centres and those involved in cancer care for Indigenous patients, provided from the literature discussed, in order to promote more culturally safe and effective care for Indigenous cancer patients.

- Indigenous involvement in the design and process of care for Indigenous cancer patients is critical. Indigenous cancer patients often describe feelings of isolation and cultural alienation, and the presence of another Indigenous person, who has survived treatment, provides comfort and hope and facilitates patient-physician communication. The presence of Indigenous health workers or Indigenous hospital liaison officers, of the same gender as the patient and who have survived cancer themselves, was especially helpful during the process of diagnosis and treatment.^{8,11} An Indigenous health worker can play multiple roles in providing care within the tertiary hospital environment and in forging better linkages with primary and community-based care.^{28–30} While design of cancer treatment facilities is important, it has been argued that managing effective treatment for Indigenous people within the current medical system requires culturally sensitive person-to-person contact, support for Indigenous family structures and a respect for the importance of place and community to Indigenous patients.³¹

- Healthcare providers should ensure, as much as possible, that cancer patients are truly informed prior to commencing treatment. Informed consent consists of five elements: competence, disclosure, understanding, voluntariness and consent.³² Attention to how communication occurs and how information is given and received is critical to understanding. The presence of an Indigenous health professional or patient advocate will help facilitate obtaining informed consent consistent with the definition earlier.

- Thought should be given to practical aspects of cancer treatment, such as the difficulties of separation from family, community and land; transportation to and from the treatment site and associated expenses; and ability to take time from work, whether domestic (childcare) or occupational. Healthcare providers should take these factors into account when developing treatment plans to promote greater treatment adherence and overall patient wellbeing. The Indigenous Women's Cancer Support Group described by Finn and colleagues shows the potential of Indigenous-led support approaches.³³

- Healthcare providers should make an effort to elicit explanatory models for cancer and to learn about the

belief system by which the Indigenous patient understands the world. If cancer is perceived as payback, and the patient believes that the use of bush medicine or Indigenous healing techniques is necessary, physicians

should work to accommodate these beliefs and also to foster open communication to ensure that treatment plans attend to the holistic health needs of their patients.

References

- 1 Australian Bureau of Statistics and Australian Institute of Health and Welfare. *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples 2005: Summary Booklet*. Canberra: Australian Institute of Health and Welfare and the Australian Bureau of Statistics; 2006; 31.
- 2 Condon JR, Armstrong BK *et al*. Cancer incidence and survival for Indigenous Australians in the northern territory. *Aust N Z J Public Health* 2005; **29**: 123–8.
- 3 Coory MD, Fagan PS *et al*. Participation in cervical cancer screening by women in rural and remote Aboriginal and Torres strait islander communities in Queensland. *Med J Aust* 2002; **177**: 544–7.
- 4 Condon JR, Cunningham J *et al*. Cancer diagnosis and treatment in the northern territory: assessing health service performance for Indigenous Australians. *Intern Med J* 2006; **36**: 498–505.
- 5 Newman C, Butow P, Knight R, McMillan K, Treloar C, Kippax S *et al*. Cancer and Aboriginal people in Australia: a review of the literature. *Crit Public Health* 2008; **18**: 65–75.
- 6 Shahid S, Finn L *et al*. 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.
- 7 Shahid S, Bleam R *et al*. 'If you don't believe it, it won't help you': use of bush medicine in treating cancer among Aboriginal people in Western Australia. *J Ethnobiol Ethnomedicine* 2010; **6**: 18.
- 8 Prior D. Don't mention the 'C' word: Aboriginal women's view of cancer. *Aborig Isl Health Work J* 2005; **29**: 7–10.
- 9 McMichael C, Kirk M *et al*. Indigenous women's perceptions of breast cancer diagnosis and treatment in Queensland. *Aust N Z J Public Health* 2000; **24**: 515–19.
- 10 McGrath P, Holewa H *et al*. Insights on Aboriginal peoples' views of cancer in Australia. *Contemp Nurse* 2006; **22**: 240–54.
- 11 Satherley Z. Hair is good but life is better. *Aborig Isl Health Work J* 2006; **30**: 7.
- 12 McGrath P, Holewa H. *The Living Model' A Resource Manual for Indigenous Palliative Care Service Delivery*. Brisbane, Australia: Researchman Publishers; 2007.
- 13 Lowell A. Communication and cultural knowledge in Aboriginal health care. Cooperative Research Centre for Aboriginal and Tropical Health; 1998.
- 14 Olver IN, Selva-Nayagam S *et al*. 'Some of us know some things and some of us know others': reducing the impact of cancer care on Aboriginal and Torres strait islander communities. *Cancer Forum* 2005; **29**: 10–13.
- 15 Cunningham J *et al*. Incidence, aetiology, and outcomes of cancer in Indigenous peoples in Australia. *Lancet Oncol* 2008; **9**: 585–95.
- 16 Franks C, Beckmann K. A qualitative analysis of patients taking their own leave from Alice Springs Hospital in 1998. *Aborig Isl Health Work J* 2002; **26**: 3–8.
- 17 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 Review*. Accepted 28 July; 2010.
- 18 Saethre EJ. Conflicting traditions, concurrent treatment: medical pluralism in remote Aboriginal Australia. *Oceania* 2007; **77**: 95–110.
- 19 Maher P. A review of 'traditional' Aboriginal health beliefs. *Aust J Rural Health* 1999; **7**: 229–36.
- 20 Boulton-Lewis G, Pillay H, Wilss L, Lewis D. Conceptions of health and illness held by Australian Aboriginal, Torres strait islander, and Papua New Guinea health sciences students. *Aust J Prim Health* 2002; **8**: 9–16.
- 21 Devanesen D. Traditional Aboriginal medicine practice in the northern territory. Paper presented at the International Symposium of Traditional Medicine, 11–13 September, 2000.
- 22 Lowenthal RM. Reducing the impact of cancer in Indigenous communities: ways forward. *Med J Aust* 2005; **182**: 105–6.
- 23 Cass A, Lowell A, Christie M, Snelling PL, Flack M, Marrnganyin B *et al*. Sharing the true stories: improving communication between Aboriginal patients and healthcare workers. *Med J Aust* 2002; **176**: 466–70.
- 24 Shahid S, Thompson SC. An overview of Indigenous cancer and their beliefs around the disease, a cross-country comparison: Australia, Canada, New Zealand and the United States. *Aust N Z J Public Health* 2009; **33**: 109–18.
- 25 Aboriginal Cancer Care Unit. 'It's Our Responsibility'. . . Report of the Aboriginal cancer care needs assessment [report on the Internet]. Ontario (CAN): Cancer Care Ontario; 2002. 2002 [cited 2010 Sep 2]. Available from URL: <http://www.cancercare.on.ca>
- 26 Burhansstipanov L. Cancer: a growing problem among American Indians and Alaska Natives. In: Dixon M, Roubideaux Y, eds. *Promises to Keep: Public Health Policy for American Indians and Alaska Natives in the 21st Century*. Washington, DC: The American Public Health Association; 2001.
- 27 Burhansstipanov L, Gilbert PHA, LaMarca K, Krebs LU. An innovative path to improving cancer care in Indian country. *Public Health Rep* 2001; **116**: 424–33. (September–October).
- 28 Taylor KP, Thompson SC, Smith JS, Dimer L, Ali M, Wood MM. Exploring the impact of an Aboriginal health worker on hospitalised Aboriginal experiences: lessons from cardiology. *Aust Health Rev* 2009; **33**: 549–57.
- 29 Croager EJ, Eades T, Pratt IS, Slevin T. Impact of a short, culturally relevant training course on cancer knowledge and confidence in western Australia's Aboriginal health professionals. *Aust N Z J Public Health* 2010; **34**: S76–79.
- 30 Waldock DJ. A review of Aboriginal health beliefs and their incorporation into modern Aboriginal health delivery systems. *Aust Health Surveyor* 1984; **16**: 3–13.
- 31 Thompson SC, Shahid S, Bessarab D, Durey A, Davidson PM. Not just bricks

and mortar: planning hospital cancer services for Aboriginal people. *BMC Res Notes* 2011; 4: 62.

32 Beauchamp TL, Childress JF. *Principles of Biomedical Ethics*, 5th edn. Oxford: Oxford University Press; 2001.

33 Finn LB, Pepper A, Gregory P, Thompson SC. Improving Indigenous access to cancer screening and treatment services: descriptive findings and a

preliminary report on the Midwest Indigenous Women's Cancer Support Group. *Australasian Medical Journal* 2008; 2: 1–21.

Mortality and its predominant causes in a large cohort of patients with biopsy-determined inflammatory myositis

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Key words

polymyositis, dermatomyositis, inclusion body myositis, mortality, Bohan and Peter criteria, standardised mortality ratio.

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Received 5 August 2010; accepted 18 October 2010.

doi:10.1111/j.1445-5994.2010.02406.x

Abstract

Background: There is a paucity of literature on the patterns and predictors of mortality in idiopathic inflammatory myopathies (IIM).

Aims: To determine the patterns and predictors of mortality in a South Australian cohort of patients with biopsy-proven IIM.

Methods: The living/deceased status (and for deceased patients the causes of death) of patients with histologically determined IIM was determined from the Births, Deaths and Marriages Registry. Standardised mortality ratios (SMR) were generated compared with the age/gender matched South Australian population. The effect of presence/absence of the components of the Bohan and Peter criteria on risk ratios (RR) for mortality was determined. The effect of comorbidities and autoantibodies on mortality was investigated.

Results: The SMR for mortality in IIM was 1.75 and was significantly increased in all disease subgroups, being highest in patients with dermatomyositis (2.40). Dominant causes of death were cardiovascular disease (31%), infections (22%) and malignancy (11%). Risk factors for death were age at time of biopsy (hazard ratio 1.05), ischaemic heart disease (RR 2.97, $P < 0.0001$), proximal weakness at diagnosis (RR 1.8, $P = 0.03$), definite diagnosis of IIM per the Bohan and Peter criteria (RR 2.14, $P < 0.0001$), and the absence of autoantibodies (RR 1.9, $P < 0.001$).

Conclusions: Patients with IIM are at 75% increased risk for mortality, and cardiovascular diseases account for the commonest causes of death. This study suggests a thorough cardiovascular evaluation of these patients is indicated, and raises the possibility that targeted interventions such as the use of aspirin or statins may improve outcomes in IIM.

Introduction

The idiopathic inflammatory myopathies (IIM) are a group of systemic autoimmune diseases with dominant

manifestations on skeletal muscle. The three best recognised disease subsets are polymyositis (PM), dermatomyositis (DM) and inclusion body myositis (IBM).¹ As for many autoimmune diseases, both genetic² and environmental³ factors are considered important, and recently there has been considerable interest in the role of myositis-specific and myositis-associated autoantibodies (MSA and MAA) in pathogenesis.⁴

Funding: Dr Vidya Limaye was the recipient of the Australian and State and Territory affiliates grant from Arthritis Australia. Conflict of interest: None.