

“I can’t do this, it’s too much”: building social inclusion in cancer diagnosis and treatment experiences of Aboriginal people, their carers and health workers

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Abstract

Objectives Social inclusion theory has been used to understand how people at the margins of society engage with service provision. The aim of this paper was to explore the cancer care experiences of Aboriginal people in NSW using a social inclusion lens.

Methods Qualitative interviews were conducted with 22 Aboriginal people with cancer, 18 carers of Aboriginal people and 16 health care workers.

Aboriginal members of the writing and research team L. Clair Jackson is Ugarapul/Githabal (Jagara Nation, SE Qld) on her father’s side and French and German on her mother’s side. She has lived mostly in Sydney, working in education, research and the arts and is now consulting as a Cultural Mentor/Advisor to APOCC and other projects in Aboriginal health at the National Centre in HIV Social Research. Veronica Saunders is of Biripi country (Taree NSW) and has worked in nursing and Aboriginal education and is now the Aboriginal Liaison Officer on the APOCC project, based at the Cancer Council NSW. She has played leading roles in Local Aboriginal Education Consultative Groups and reconciliation, working closely with Aboriginal and non-Aboriginal people. Priscilla Johnson is from Cherbourg QLD (Waka Waka and Birri Gubbi) and besides working on the APOCC team, also works in the Aboriginal Mental Health Unit, part of the Camperdown Community Health Centre. Priscilla has directed the focus of her work around grief and loss, through healing and mediation.

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Results Participants’ narratives described experiences that could be considered to be situational factors in social inclusion such as difficulties in managing the practical and logistic aspects of accessing cancer care. Three factors were identified as processes of social inclusion that tied these experiences together including socio-economic security, trust (or mistrust arising from historic and current experience of discrimination), and difficulties in knowing the system of cancer treatment.

Conclusions These three factors may act as barriers to the social inclusion of Aboriginal people in cancer treatment. This challenges the cancer care system to work to acknowledge these forces and create practical and symbolic responses, in partnership with Aboriginal people, communities and health organisations.

Keywords Australia · Aborigine · Cancer · Treatment ·
Diagnosis · Trust · Socio economic security

Introduction

Since colonization, Aboriginal and Torres Strait Islander Australians (thereafter Aboriginal Australians) have

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managed their health in diverse ways. Aboriginal Australian peoples, communities and more recently community controlled health organisations have sought to prioritise a holistic approach to health that includes physical, emotional, social and spiritual aspects (Couzos and Murray 2007).

Over time, new health issues have emerged for Aboriginal Australians, such as cancer. Improvements in identification of Aboriginal people in cancer information systems have led to greater research and advocacy to acknowledge the increasing significance of the cancer experience in Aboriginal life (Zhao and Dempsey 2006; Cunningham et al. 2008; Australian Institute of Health and Welfare 2011; Garvey et al. 2011).

Aboriginal Australians have poorer cancer outcomes despite overall improvements in cancer outcomes for Australians (Australian Bureau of Statistics and Australian Institute of Health and Welfare 2008). Engagement in cancer care for Aboriginal Australians is lower at all levels including screening, early presentation at diagnosis, continuity of care, compliance with treatment and five-year survival rates (Cunningham et al. 2008). For example, Aboriginal Australians are less likely to be diagnosed with cancer, incidence rates of some cancers are significantly higher than for non-Aboriginal Australians (incidence of cervical cancer is three times higher for Aboriginal Australians and cancers of unknown primary site and of the lung are 2.0 and 1.6 times higher than non-Aboriginal Australians); Aboriginal women are less likely to be screened for breast cancer than non-Aboriginal women (36 vs. 55%); Aboriginal Australians aged 35–64 years have higher cancer mortality rates than non-Aboriginal Australians (Australian Institute of Health and Welfare 2011). Although an emerging health concern, current evidence suggests that cancer outcomes for Aboriginal Australians resemble those for other conditions and are shaped by deeply entrenched and intersecting disadvantages (Commonwealth of Australia 2009).

In recent years, a significant body of work has emerged in Australia, particularly from Western Australia, examining the experience of Aboriginal people with cancer, including beliefs about cancer, communication issues, bush medicine and structural and practical concerns in relation to cancer treatment (Shahid et al. 2009a, b, 2010, 2011). This work critiqued current health systems for persisting with a focus on clinical competence of health professionals at the expense of psychosocial characteristics that engender trust in the patient (Shahid et al. 2009b). Infrastructure necessities for Aboriginal patients, particularly instrumental and emotional support, are noted with recommendations for greater participation and representation of Aboriginal people in decision making bodies (Shahid et al. 2009b). While a 2008 review of the literature argued that an

understanding of Aboriginal people's experience of cancer must take account of the social, economic and cultural context of people's lives (Newman et al. 2008), there has been little work which focuses on the intersection of these issues with health policy and service delivery.

Social inclusion (or exclusion) is one way of examining how people at the margins of society experience poor service provision (Marmot 2003) and can contribute to measuring, understanding and addressing social disadvantage. Social inclusion is the extent to which people and groups have access to and are integrated into the different institutions (including hospitals) and social relations of "everyday life" and the extent to which people and groups "feel part of" or feel included in society at an everyday level (Commission of the European Communities 1993; Ward et al. 2011). Elements of disadvantage such as poverty, deprivation and structural violence have been shown to be important determinants of health and access to health services (Farmer 1997; Marmot 2003). Social exclusion accounts not only for income poverty but also broader factors such as access to resources and services, social relationships, and social and economic participation. Notably, social exclusion focuses on the factors that accompany or lead to poverty, including homelessness, poor health, resource-poor social networks, discrimination and disability (Arthurson and Jacobs 2004; Saunders et al. 2008). Further, social exclusion can be considered a dynamic and inter-relating process, rather than as a situation represented by discrete measures or indicators (Hunter and Jordan 2010). Seeing social exclusion as a process directs attention to the actions of individuals or institutions that may work to exclude, or include, Aboriginal people in cancer care (Atkinson and Hills 1998). Examination of the cultural dimensions of social inclusion and exclusion (Hunter 2008) must also acknowledge the preference and choice of some Aboriginal Australians not to be included in mainstream society because of historical or current experiences of racism (Norris 2001; Hunter and Jordan 2010).

The Australian health care system operates in both public and private spheres. Cancer care is typically provided by publicly funded services, though some private doctors or facilities may be involved in some areas. People with low incomes are afforded additional benefits (such as subsidised medications). Some large public hospitals employ Aboriginal liaison officers to ensure Aboriginal patients have equitable access to care. In the context of cancer care, where there is no alternative but to engage in mainstream tertiary health systems, it is worth exploring how Aboriginal people make choices about and experience their care using a social inclusion lens. The aim of this paper was to examine accounts of cancer care for processes that exclude Aboriginal people in NSW from the everyday

aspects of care and concomitantly, for processes that could be employed to enhance social inclusion among Aboriginal people in this context. This is important, as any change to promote inclusive cancer care services for Aboriginal people must work not just with the immediate situation of social exclusion, but to understand the processes that work to deeply entrench multiple disadvantage and exclusion of Aboriginal people in many areas of life.

Methods

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

This paper presents findings from interviews conducted with three groups of people between 2008 and 2011: (1) 22 Aboriginal people who had been diagnosed with cancer (2) 18 people who were carers of Aboriginal people with cancer and (3) 16 health care workers. Cancer patients, their carers and health professionals who work with Aboriginal people with cancer were recruited from Aboriginal Medical Services (AMSs), hospital oncology services, palliative care facilities and personal networks. Flyers advertising the study were placed in AMSs and were given to oncology staff at hospitals to provide to potential participants with a toll free telephone number to contact regarding participation. Additional recruitment occurred via referral from participants and existing community contacts of Aboriginal researchers. Interviews were conducted at a location convenient to the participant and took 1.5–2 h. Trained Aboriginal interviewers (PJ, VS, CJ) conducted the majority of the interviews with Aboriginal people with cancer and with their carers. The health worker interviews were all conducted by experienced non-Aboriginal interviewers.

Participants were asked to talk about their personal and/or professional experiences with cancer including their understanding of cancer, thoughts about the Aboriginal community and issues around cancer, personal experience of cancer diagnosis and treatment or experiences caring for or working with someone with cancer at diagnosis and during treatment. Participants were also asked to provide some of their background and demographic data. As is standard in this type of research, participants were acknowledged for their time and effort (Davidson and Page 2012). Patient and carer participants were provided \$60, and health care workers were offered a \$30 gift voucher. This project was approved by the human research ethics committees of the

Aboriginal Health and Medical Research Council, The University of New South Wales, relevant committees of local health authorities and the Cancer Council New South Wales.

The interviews were digitally recorded and then transcribed. Transcripts were checked in two phases. First, the cultural mentor/advisor to the project (CJ) provided commentary and clarification on Aboriginal language and terms used including notes on emerging themes across interviews. Second, the transcripts were checked for other issues of accuracy and de-identified (removal of identifying information and application of pseudonyms). Interview data were managed using the computer software package NVivo 9 and coded for six major themes. These themes were developed through ongoing workshops with staff who had conducted interviews and from the literature (relating to both Aboriginal and non-Aboriginal peoples’ experience of cancer care).

To inform this analysis, we drew upon Thorne’s notion of interpretive description (Thorne et al. 2004; Thorne 2008) in which researchers are urged to extend their gaze beyond generic qualitative description to that of interpretive explanation addressing questions such as how are the phenomena similar or different, how do they relate to each other, what patterns exist and how do they operate? While we understand the primary social and lifestyle situational factors associated with social inclusion (such as poverty, homelessness, poor health service access), we wanted to shift our view of social inclusion to consider other interpretations of it (Thorne 2008). Thorne describes the potential of interpretive description as being able to illuminate complexities of experience into a coherence that can inform health care policy. Thus, we wanted to move beyond a situational understanding of social inclusion/exclusion to engage with the processes that could support inclusive practices for Aboriginal people requiring cancer care.

Close reading of the data was conducted by the lead author (CT) in which situational aspects of social inclusion drawn from the literature were identified such as isolation and financial concerns. Three overarching themes were then identified that tied together, in the form of processes, elements of social inclusion evident in participants’ experiences (socio-economic security; trust; understanding the system). A draft of the paper was provided to the Aboriginal researchers (CJ, VS, PJ) for their comment in a workshop style discussion. The paper was also reviewed by the ethics committee of the Aboriginal Health and Medical Research Council.

Results

Demographic details of patient, carer and health worker participants are reported in Table 1. Of the 22 patient participants, eight reported that they were working full or part-time, four reported receiving sickness benefits and

Table 1 Demographic characteristics of the patient, carer and health worker participants

	Patient	Carer	Health worker
Females	16	16	11
Males	6	2	5
Identify as Aboriginal	22	14	8
Decade of birth			
1940s	3	2	
1950s	9	4	
1960s	4	6	
1970s	2	3	
1980s	1	1	
Not reported	3	2	16

another four reported that they were not working. Work status was not reported by six participants. Of the 18 carer participants, eight reported caring for a parent with cancer, five for their spouse or partner, two for their daughter, one for their sibling and two participants for more than one family member with cancer.

The 16 health worker participants were employed in a range of settings and diverse roles including ten in urban settings, two in coastal settings, and four in rural settings. Professional roles included three oncologists, two educators, four liaison workers, two nursing specialists, one cancer coordinator, one dietician, one health service manager, one general practitioner and one men's health worker. In relation to experience and engagement with Aboriginal patients, ten described their experience as limited and six as extensive.

Our data drew out the everyday practical and logistical issues that impact Aboriginal people's experience of cancer treatment that can be understood to represent situational aspects of social exclusion including transport and accommodation, the alienation experienced within hospital environments, costs associated with medication and treatment and relative scarcity of Aboriginal liaison support workers. As these issues have been well covered in the literature (Shahid et al. 2011), we will focus in this paper on the three process factors—socio-economic status, knowing the system and trust—that offered a conceptual link to understand how these key issues conspired to complicate the achievement of social inclusion for Aboriginal people in their cancer care services.

Understanding the profound impact of reduced socio-economic status and security in building social inclusion in cancer care

Overall, Aboriginal people occupy lower socio-economic status bands than non-Aboriginal people (Norris 2011), and poverty is an obvious and foundational aspect of social

exclusion. However, considering social exclusion as a process rather than a situation directs our attention to examining not only the resources available to an individual patient or immediate family, but also those available to the broader family and community network. This means that Aboriginal people may have fewer resources available as a buffer or reserve to cope with emergencies such as cancer treatment. As indicated by Alana and Evelyn, this fundamentally shapes the experience of health care.

Well financially it is a massive ... the cost of treatment for indigenous people with cancer is ... a huge burden on them and because most of them are unemployed or are on social security benefits and so ... the cost of going to Cancer Council, especially if they are attached to a private hospital, it can be quite costly. It's about \$300 a pop for one appointment, for a radio therapy or ... for other types of therapy. So it's very costly there (Alana, Aboriginal health care worker)

By just about any social index, we are an oppressed minority. And the kind of powerless and lack of material sources means that we have a different experience (Evelyn, Aboriginal health care worker)

Recognising the role of (mis)trust of mainstream health systems in building social inclusion in cancer care

Participants (both Aboriginal and non-Aboriginal) reflected that for Aboriginal Australians, a collective experience of racism and marginalisation has led to widespread distrust of institutions of mainstream society, such as health care. Aboriginal Australians may face exclusionary processes or choose not to engage with these institutions for fear of future negative treatment. Zeta (patient) described how racist practices of antenatal care for her mother (being made to wait outside the hospital until all non-Aboriginal patients had been seen) had resulted in her family being "fearful" of hospitals. These past experiences had permeated Zeta's decisions about and perceptions of trust in the cancer treatment system. Similarly, Tanya and Max describe ways in which fear or mistrust of the health system can be directly linked to decisions about engaging or avoiding cancer care.

Just that fear of being treated differently and not wanting to put yourself in a position for that. (Max, patient)

Every time [my partner] goes into the hospital, he is treated like a piece of dirt. And then he ends up discharging himself because he doesn't get proper treatment (Tanya, non-Aboriginal carer)

Challenging the reduced awareness of cancer care systems in building social inclusion in cancer care

Being diagnosed with cancer or undergoing treatment can involve, for many people, being provided with a significant amount of technical information. Diagnosis can mean having to engage with an unfamiliar health system with which many will have had little previous experience. Aboriginal and non-Aboriginal patient and carer participants described confusion about financial assistance programs resulting in the lack of uptake of support for transport, temporary accommodation and housing expenses. Patient and carer participants described a process of ad hoc informal information acquisition provided by family and peers. Desley (patient) felt that she did not understand the ways in which cancer care was organised and further suggested that this lack of knowledge could present a significant barrier to cancer treatment and care for other Aboriginal people.

So cancer, you hear of people on a waiting list and you say to yourself, "well why did you have to wait?". And then I look at myself and say, "Well I didn't have to wait. Now what stopped me from waiting? Is it that health fund I paid into? Or is it where I happen to be?". I don't know the answer to that. But yeah, I can see that some Aboriginal people ... they are not into the system. If you don't know the system, which is hard to know, you got to take a lot of it in and you got to listen to a lot of things, if you can't take that on board ...you would be stuck. You would walk away and say "I can't do this, it's too much". (Desley)

Loretta (patient) used the metaphor of an unknowable journey through cancer care to position her suggestion for a "mentor".

I think ... there needs to be a ...a person ... not necessarily a case worker but a, a support worker, ideally an Aboriginal person who has ... some awareness about cancer, has an awareness about the referral pathways, that they can support. So I would like to see that there is someone... who has the empathy or understanding about Aboriginal people and culture and that they can ...it's not the right kind of word but almost mentor you through that whole ...you know, that knows the journey, ... often it's a journey you travel once and ...you don't know where you are going, you don't. (Loretta)

Kimberley (patient) spoke of the difficulties in accessing financial assistance for cancer care. She believed that her work in the allied health sector provided her with "the knowledge" that other Aboriginal people may not have. However, she was unable to access financial assistance and

link this with her perception that Aboriginal people are stereotyped, a process underlying mistrust in mainstream health systems.

They say in the information there's financial assistance available, but they don't explain that you'll be assessed. ... I was never assessed and because I stayed working in the community sector ... I am one of the lucky ones too I suppose to have the knowledge. But you know, it's like you're begging for like financial help and them not listening. I think you just get stereotyped as like ...you know, it's not fair. (Kimberley)

In another example, Bonnie (Aboriginal Liaison Officer in a hospital) brings together the issues of travel costs and Aboriginal people not "knowing the system". Bonnie helps Aboriginal people navigate a complex system to ensure that they have ongoing access to cancer treatment. Bonnie also signals the importance of local services working to support cancer patients and their carers to negotiate a system they may not trust in order to optimise their opportunity for cancer care.

Because money is always the issue. Aboriginal people don't understand the systems. We are not inclined to understand that. You've got to put this form in, they've got to do that form, its very important to do those forms ... Because Aboriginal people aren't aware of those systems, so you've got to be able to educate them. And you've got to rely on the local health to be able to keep that going.

Discussion

This study aimed to examine the processes that impact on building social inclusion of Aboriginal people in cancer care. These data illuminate the immediate factors apparent in relation to social exclusion (such as poverty and isolation) as well as an understanding of the processes underpinning these, to develop more nuanced approaches to building social inclusion in cancer care. Participant excerpts demonstrate the compounding processes that can hinder patients and carers engaging with health and allied services in effectively managing their cancer diagnosis and treatment needs. In addition to managing the potential shock and grief a cancer diagnosis can inspire, participants described the ways in which patients and carers navigate unfamiliar systems in order to counteract the barriers that relate to racial inequality, poverty and related disadvantage. In so doing, participants articulated the ways in which Aboriginal patients, and their carers, may make decisions to avoid or cease cancer treatment.

These findings support previous research (Shahid et al. 2011) suggesting similarities of experiences for Aboriginal people and communities across Australia and that the difficulties that Aboriginal Australians face are entrenched in systems of delivery of health care and other services. Aboriginal Australians face difficulty in managing the practical and logistical aspects of accessing cancer care, particularly factors related to financial burdens, transport, accommodation and isolation. Evident in participants accounts were practical recommendations [which have been made before (Loppie and Wien 2005; Shahid et al. 2011)] such as increasing numbers of Aboriginal health staff, drawing on the support that families of Aboriginal patients can provide and assistance with costs and logistics of treatment provided directly to the patient (such as in the form of cash) or by other services (such as could be provided by local community transport). However, in some situations these services may exist but be underutilised by Aboriginal clients. This underlines the importance of understanding the processes that influence Aboriginal people in deciding whether to use such services.

Socio-economic status has been widely documented as immediately and significantly associated with health care access and outcomes (Wilkinson 1999) and as fundamental to understanding social inclusion. A related issue to consider here is socio-economic security which can determine access to and use of a range of resources that provide protection from poverty and other forms of material disadvantage (Ward et al. 2011). The lack of access for many Aboriginal Australians to the mainstream economy (Norris 2011) contributes to vulnerability and inequitable access to health care and other services that require (or are perceived to require) out of pocket payments. Being able to direct Aboriginal people to immediate assistance (financial, material and other) rather than reimbursement of costs, for example, will ameliorate additional burdens on those who have least resources, or buffers, to meet these demands. However, the means by which these services are offered is also important to foster social inclusion.

The second process of social inclusion identified here is trust. Trust has been shown to be essential to effective health care interactions and shapes patients' decisions about following doctor's advice and taking medication (Mechanic and Meyer 2000). Trust for Aboriginal communities is inherently tied to historical and contemporary experiences of colonisation, dislocation and racism, as was demonstrated by these data. Any innovation in health care to promote inclusion of Aboriginal Australians must work to address deep mistrust in mainstream health systems. Genuine and meaningful partnership work with Aboriginal community controlled health organisations is a practical way forward to improve the standing of cancer services in Aboriginal communities.

The final inter-related process of social inclusion relates to Aboriginal people knowing the health system. Our data show that Aboriginal people, who may have previously only engaged with community controlled health organisations, may not understand the complex mainstream tertiary cancer care system and further may not trust that system and fear the costs of engaging with it. To bridge the gap between the needs of patients and the organisation of the health system requires an appreciation of the interplay of these factors. A practical means to bridge this gap are patient navigator programs that have been operating in the USA for more than two decades (Linda Burhansstipanov et al. 1998) and were established to support people with low incomes who faced many of the barriers described here: widespread financial barriers; logistical barriers including transport; and, socio-cultural barriers such as limited social support and inadequate health literacy (Wells et al. 2008; Center to Reduce Cancer Health Disparities; Whop et al. 2012).

This study was able to recruit a sample of Aboriginal people who had experienced cancer, carers and health workers. Most participants were female and lived in the eastern areas (metropolitan and non-metropolitan) of NSW. These data may be less applicable to men and those who live in more regional or rural areas, particularly those areas with limited health infrastructure. Those who self-selected to participate in this study, and were contactable via our recruitment strategies, may not be representative of other Aboriginal people or health workers in NSW. We aimed to avoid furthering the discourse of "deficiency" or "pathology" of Aboriginal people and communities (Kowal and Paradies 2010), hence framed this paper in relation to building social inclusion. In doing that, we needed to examine the factors and processes that were working against social inclusion, necessitating the focus on social exclusion at some points. Future research could examine the implementation of processes to support social inclusion for Aboriginal people requiring cancer care.

Using the lens of social inclusion we have examined the extent to which, and the processes that underpin how, Aboriginal Australians feel and experience being "part of" the mainstream cancer care and treatment system. These data would suggest that the cancer care and treatment system (which is, in itself, complex and multiple) is not well understood and is perceived as alien and often unwelcoming. Today, it is well accepted that official ceremonies begin with a welcome to country—that Aboriginal and non-Aboriginal people are welcomed by their Aboriginal hosts. The purpose of this welcoming is to make visitors feel accepted and safe in that country. Perhaps a parallel needs to be made in the mainstream health system for bettering inclusion of Aboriginal people in cancer care (supported by policies and programs). Cancer

care and treatment services could develop ways in which to "welcome" Aboriginal people to their "country" of hospital, clinic or specialist protocols, to explain and facilitate its customs and assist the patient to feel accepted and safe in this alien place.

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References

- Arthurson K, Jacobs K (2004) A critique of the concept of social exclusion and its utility for Australian social housing policy. *Aust J Soc Issues* 39(1):25–41
- Atkinson A, Hills J (1998) Exclusion, employment and opportunity. LSE STICERD Research Paper No. CASE004. Centre for Analysis of Social Exclusion, London
- Australian Bureau of Statistics and Australian Institute of Health and Welfare (2008) The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples 2008. Canberra, ABS and AIHW (ABS Cat. No. 4704.0; AIHW Cat. No. IHW 21)
- Australian Institute of Health and Welfare (2011) The health and welfare of Australia's Aboriginal and Torres Strait Islander people, an overview 2011. AIHW, Canberra
- Center to Reduce Cancer Health Disparities. "Patient Navigation research program". <http://crchd.cancer.gov/pnp/pnpr-index.html>. Retrieved Accessed 16 Nov 2011
- Commission of the European Communities (1993) Background Report: Social Exclusion—Poverty and Other Social Problems in the European Community, ISEC/B11/93. Office for Official Publications of the European Communities, Luxembourg
- Commonwealth of Australia (2009) Closing the gap on indigenous disadvantage: the challenge for Australia. Commonwealth of Australia, Canberra
- Couzos S, Murray R (2007) Aboriginal primary health care: an evidence-based approach. Oxford University Press, South Melbourne
- Cunningham J, Rumbold A et al (2008) Incidence, aetiology, and outcomes of cancer in Indigenous peoples in Australia. *Lancet Oncol* 9:585–595
- Davidson P, Page K (2012) Research participation as work: comparing the perspectives of researchers and economically marginalized populations. *Am J Public Health* 102(7):1254–1259
- Farmer P (1997) Social scientists and the new tuberculosis. *Soc Sci Med* 44(3):347–358
- Garvey G, Cunningham J et al (2011) Reducing the burden of cancer for Aboriginal and Torres Strait Islander Australians: time for a coordinated, collaborative, priority-driven, Indigenous-led research program. *Med J Aust* 194(10):530–531
- Hunter B (2008) Indigenous social exclusion: insights and challenges for the concept of social inclusion. *Social Inclusion Down Under* Symposium, University of Melbourne, The Brotherhood of St Laurence
- Hunter B, Jordan K (2010) Explaining social exclusion: towards social inclusion for Indigenous Australians. *Aust J Social Issues* 45(2):243–265
- Kowal E, Paradies Y (2010) Enduring dilemmas of Indigenous health: recognising the tensions inherent in all efforts to bring about change in Indigenous health outcomes. *MJA* 192(10):599–600
- Linda Burhansstipanov L, Bad Wound D et al (1998) Culturally relevant "Navigator" patient support the native sisters. *Cancer Pract* 6(3):191–194
- Loppie C, Wien F (2005) Our journey: first nations experience of navigating cancer care. *Cancer Care Nova Scotia*, Halifax
- Marmot M (2003) Understanding social inequalities in health. *Perspect Biol Med* 46(3):S9–S23
- Mechanic D, Meyer S (2000) Concepts of trust among patients with serious illness. *Soc Sci Med* 51:657–668
- Newman C, Butow P et al (2008) Cancer and Aboriginal people in Australia: a review of the literature. *Crit Public Health* 18(1):65–75
- Norris R (2001) Australian Indigenous Employment Disadvantage: What, why and where to from here? *J Econ Social Policy* 5(2): Article 2
- Norris R (2011) The more things change... the origins and impact of Australian Indigenous economic exclusion. Brisbane, Post Pressed
- Saunders P, Naidoo Y et al (2008) Towards new indicators of disadvantage: deprivation and social exclusion in Australia. *Aust J Soc Issues* 43(2):175
- Shahid S, Finn L et al (2009a) Understanding, beliefs and perspectives of Aboriginal people in Western Australia about cancer and its impact on access to cancer services. *BMC Health Serv Res* 9(132):1–9
- Shahid S, Finn L et al (2009b) Barriers to participation of Aboriginal people in cancer care: communication in the hospital setting. *Med J Aust* 190(10):574–579
- Shahid S, Bleam R et al (2010) 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 Ethnomed* 6:1–22
- Shahid S, Finn L et al (2011) 'Nowhere to room ... nobody told them': logistical and cultural impediments to Aboriginal peoples' participation in cancer treatment. *Aust Health Rev* 35:235–241
- Thorne S (2008) Interpretive description. Left Coast Print, Inc, Walnut Creek
- Thorne S, Reimer Kirkham S et al (2004) The analytic challenge in interpretive description. *Int J Qual Methods* 3(1):1–15
- Ward P, Meyer S, et al (2011) Complex problems require complex solutions: the utility of social quality theory for addressing the Social Determinants of Health. *BMC Pub Health* 11:630
- Wells K, Battaglia T et al (2008) Patient navigation: state of the art, or is it science? *Cancer* 15(113):8
- Whop L, Valery P et al (2012) Navigating the cancer journey: a review of patient navigator programs for Indigenous cancer patients. *Asia-Pac J Clin Oncol* 8(4):e89–e96
- Wilkinson R (1999) Putting the picture together: prosperity, redistribution, health and welfare. In: Marmot M, Wilkinson R (eds) *Social determinants of health*. Oxford University Press, Oxford
- Zhao Y, Dempsey K (2006) Causes of inequality in life expectancy between Indigenous and non-Indigenous people in the Northern Territory, 1981–2000: a decomposition analysis. *Med J Aust* 184(10):490–494