

Improving Indigenous access to cancer screening and treatment services: descriptive findings and a preliminary report on the Midwest Indigenous Women's Cancer Support Group

Lisabeth D Finn¹, Annette Pepper^{1,2}, Pauline Gregory², Sandra C Thompson^{1§}

¹Centre for International Health, Curtin University of Technology, Box U1987, Perth, Western Australia

²Midwest Indigenous Women's Cancer Support Group, Geraldton

Email addresses:

LDF: l.finn@curtin.edu.au

AP: pepper60@bigpond.com

PG: pauline.gregory@grams.asn.au

SCT: s.thompson@curtin.edu.au

Keywords: Cancer, Support Group, Aboriginal, Indigenous, Partnerships

Abstract

Background

Higher cancer morbidity and mortality rates for the Indigenous population compared to the overall Australian population has underlined the critical need to improve access for Aboriginal people to cancer treatment services. This paper describes an Indigenous Women's Cancer Support Group (IWCSG) established to support Indigenous people with cancer and their carers/relatives and to facilitate Aboriginal access to cancer screening and treatment. Preliminary findings from an evaluation of the group are presented.

Methods

The study employed qualitative research methods to describe IWCSG operations and investigate the group's effectiveness. It included one-on-one interviews with 11 Geraldton-based health service providers, the IWCSG coordinator, and 10 women who have been linked to IWCSG support, as well as observation of group meetings.

Results

Descriptive outcomes relate to group operations, group effectiveness, group benefits and future development of the group. A cultural strength of IWCSG is its ability to operate confidentially behind the scenes, providing emotional support and practical help directly to Indigenous people concerned about privacy and shame issues. The important cultural role IWCSG plays in overcoming communication and other cultural barriers to accessing cancer treatment was unanimously recognised by health service providers. Aboriginal women supported by IWCSG spoke about an increased sense of safety, trust and support in accessing and navigating mainstream cancer services. A critical issue emerging from the research is the need for further

development of effective collaborative working relationships between IWCSG members and health service providers.

Conclusions

The IWCSG has the potential to inform an effective model for facilitating Indigenous access both to cancer treatment and to mainstream treatment for a variety of health problems. Future research is required to explore the applicability of Indigenous support groups and to focus on the development of effective collaborative partnerships between Indigenous people and non-Aboriginal health service providers.



Background

While the incidence of cancer overall in Indigenous Australians is less than that in the overall Australian population, Indigenous people are less likely to access early detection and medical treatment, resulting in higher mortality and morbidity rates^{1,2,3}. Barriers that limit access among Aboriginal people include lack of understanding about cancer and its treatment, fear⁴, communication difficulties, and cultural alienation within the infrastructure of the westernised medical system^{5,6,7}. These concerns are not exclusively experienced by Aboriginal people⁸, however there is evidence in countries including Australia, Canada, New Zealand and the USA that they present more substantial difficulties for Indigenous populations⁹.

This paper describes the Midwest Indigenous Women's Cancer Support Group (IWCSG) which began operating in Geraldton, a regional town some 500 kilometres north of Western Australia's capital city Perth. The aim of the group is to provide support to Aboriginal women with cancer, as well as female carers and relatives. No other Indigenous cancer support group of this kind has previously been set up in Western Australia (WA). While the term Aboriginal and Torres Strait Islander people is the preferred term for the First Nations people of Australia, "Aboriginal" is generally preferred within Western Australia, and is generally preferred over use of the term "Indigenous". However, in naming their group, the members of the IWCSG wanted to be inclusive as they were aware of a Maori woman in the area who might not access support if it was titled as an "Aboriginal" group.

The initiative arose when an Aboriginal health worker was involved in research to identify the nature of support needed to assist Indigenous people with cancer. She

successfully applied for a six-month Health Promotion Scholarship with the aim of setting up an Indigenous women's cancer support group. Within six months, she had engaged many local Aboriginal women and relevant health service providers, and the IWCSG was established with her playing the major role of coordinating and organising the group. By the end of her scholarship, local health service providers and the Geraldton Regional Aboriginal Medical Services (GRAMS) recognised the potential of the group. This was demonstrated when the WA Country Health Service Midwest Social Work Department, based at Geraldton Regional Hospital, provided further funding to continue her role as a part-time (0.2 full-time equivalent) group coordinator for a further six months.

A literature review of partnerships between Indigenous and mainstream health service providers has highlighted the need for collaborative interventions between the different service providers to address chronic health and social issues. The review found little evidence of research concerning ways of undertaking mutually supportive, empowering and sustainable engagements in health collaborations between Aboriginal and mainstream health service providers¹⁰.and highlighted the need to build an evidence base on how to undertake mutually supportive, empowering and sustainable engagements. From its earliest history IWCSG has been proactive in forming working partnerships and links with formal cancer, palliative care and allied health services operating out of Geraldton Hospital, as well as with non-government cancer support and welfare agencies. Early in the group's history, IWCSG invited representatives from a total of 20 cancer-related services to a meeting to discuss IWCSG aims and how it could best operate within the extant cancer service network. The Group has also established robust linkages with the local Aboriginal Community

Controlled Health Service. IWCSG has developed ongoing links with the Geraldton Regional Aboriginal Medical Services which is currently administering the group's funding. The group has potential in terms of facilitating Aboriginal access to cancer screening and treatment, and potentially to serve as a model for support groups for the Indigenous population for other serious chronic diseases in both metropolitan and regional areas. Lessons learnt from the group can help fill the research gap on ways of negotiating effective collaborative partnerships between Indigenous and mainstream health service providers.

The current paper provides a description of the operations of the IWCSG, with a particular focus on the ways the group may benefit local Indigenous women and health service providers. The findings are preliminary, providing a broad overview of the major issues which emerged and more comprehensive data analysis of transcribed interviews is planned. This approach is considered necessary given the need to approach funders for financial support to assist the ongoing operations of the group. Preliminary recommendations are made regarding ways the IWCSG can develop in the future.

Methods

The literature highlights the need to develop culturally sensitive research approaches with Indigenous research participants. Given the distrust that many Aboriginal people have of research, it is important to build a relationship with IWCSG participants by 'yarning' with them rather than confronting them with questions both prior to and as part of the action research process. Descriptive qualitative research methods were chosen for a number of reasons. Firstly, descriptive research is appropriate with the

formative research work which this study represented. Interviews soliciting narratives and storytelling about experiences with cancer and with the IWCSG were sought from Indigenous participants. This mode was used since ‘yarning’ is an acceptable means of gathering data aligning with Indigenous cultural oral traditions and providing a culturally sensitive research method which allowed indigenous people to have voice¹¹. The qualitative research paradigm also aligns with the non-positivist approach of Aboriginal people whose approach leans towards understanding the ever-changing lived experience of people, rather than uncovering an immutable truth about experience of a phenomena¹², and this approach was considered non-threatening to Aboriginal stakeholders in the group. Interviews were undertaken with 11 Geraldton-based health service providers, the IWCSG coordinator, and 10 women who have been linked to IWCSG support. Health service providers interviewed included key informants from the Geraldton Regional Aboriginal Medical Service and key cancer service providers at Geraldton Regional Hospital in the areas of nursing, palliative care, population health, social work and a non-government cancer support agency. Apart from the Coordinator and one IWCSG founder member who were chosen for interview as key informants, the other IWCSG interviewees were a convenience sample and included Indigenous women with cancer and carers/relatives. At this preliminary phase, only 3 group meetings, held on a fortnightly basis, were observed over the four field research trips from Perth to Geraldton to gather data. The investigation formed part of a larger research project into Indigenous cancer which had gained ethics approval from the Western Australian Aboriginal Health Information and Ethics Committee (WAAHIEC) and the Curtin University Human Research Ethics Committee.

The interviews sought to examine health service providers' views of the role and effectiveness of IWCSG and avenues for its future development. Interviews with women who have accessed IWCSG support sought to determine how the group had helped them both to cope with cancer and to gain greater understanding about cancer screening and treatment. A focus group was also conducted with Aboriginal women in a small regional town who are seeking, along with other women from a wider region, to access IWCSG on a regular basis to provide cancer support and education.

Thematic analysis was employed to analyze the qualitative data. This mode of analysis was considered appropriate in that it is able to provide a rich overall thematic description, particularly when an under-researched area is being investigated. An advantage of thematic analysis is that it is independent of theory and epistemology and as such provides a useful and flexible research tool which can provide a detailed as well as complex description of the data¹³.

Results

Four main themes emerged from analysis of the qualitative data. These can be usefully categorised under the headings of description of IWCSG operations, group effectiveness, group benefits and development of collaborative partnerships.

Group operations

IWCSG meetings take place once a fortnight in a community facility. They begin with an informal lunch and opportunity to chat, before moving into the business of the day. At the three meetings observed, the number of Indigenous participants varied from 3 to 6. Attendance by invited health service providers from Geraldton Regional

Hospital-based cancer services and from Geraldton Regional Aboriginal Medical Service varied from 2 to 8 over the 3 group meetings. Health service providers were invited to allow Indigenous women with cancer or carers/relatives to become familiar with them and to obtain information and assistance. At one of the meetings, education was given about palliative care with question time, and several Indigenous relatives/carers asked for information about issues including medication, diet and ways of preventing bedsores.

Interviews and observation of IWCSG meetings indicated that group meetings provided share and care opportunities where Indigenous people with cancer and carers/relatives were able to express their fears and difficulties. One Indigenous woman, who had undertaken cancer treatment in Perth, shared that her hospital treatment experiences made her feel useful because it helped women who were afraid of pending treatment. Another carer spoke about the relief she felt when she was able to share her grief about her husband's condition at the group, something she was unable to do in her own family where she felt she had to keep up a strong front.

Importantly, non-Aboriginal health service providers who had attended IWCSG meetings reported that they had the opportunity to tap into Indigenous input into the care and support of Aboriginal women with cancer, and to learn about some of the issues underpinning the reasons why Indigenous people may not have been accessing cancer support services.

“...the awareness that is brought to all the different service providers through this group, the understanding of a lot of stuff they didn't understand before. It was brought to them through this group that the shame factor is a genuine thing amongst Aboriginal women. The cultural side of things, why they don't keep appointments and stuff, how petrified

they are when they go down to Perth and see these big hospitals, and they say they are not going back.” [IWCSG member]

As a result of attending the group meetings on a regular basis, a special project officer with Geraldton Palliative Care Service worked with the IWCSG to draw up a guide for service providers outlining appropriate cultural care for Aboriginal people. The group meetings provided opportunities for informal discussion and for service providers to build relationships with the Aboriginal women attending the group and this led to insights into the realities of daily life for Aboriginal people including the difficulties and grief that Aboriginal people too often face in a number of domains of their life. This helps contextualize why Aboriginal people may not focus on their health, even in the face of a life-threatening illness.

The group was described by a health service provider as being ‘organic’ in its development, adapting its operations along the way to suit the needs of individuals . A key IWCSG informant said that unless a special educational talk was planned for a group meeting, group proceedings largely developed out of the needs of Indigenous people attending on the day. IWCSG members spoke about the need for the group not to be highly structured as this does not suit Aboriginal culture. Rather the group provides an opportunity for lunch and ‘yarning’ where Aboriginal people could feel comfortable and safe first, and then share problems or receive education about cancer as a secondary factor. Given reported issues of Aboriginal shame around illness and a concern to maintain privacy, one of IWCSG’s strengths is its active operation as a support group via a ‘grapevine’ or ‘bush telegraph’, where Indigenous women with cancer and carers/relatives are contacted and supported by IWCSG members confidentially behind the scenes in their homes.

“Bush telegraph is a good way of describing how we operate because we do talk a lot you know. So it is a way of communicating with people, of finding out who needs help. Aboriginal people are careful about privacy, they don’t want everyone to know their business, so we go to their homes to ask them if we can help them in any way.” [IWCSG member]

Thus, not all referrals to the group occur through health service providers following a diagnosis, and the group is proactive about entering affected community members’ members homes in a way that would not occur through mainstream health services.

Cancer nurses, social workers and a non-government cancer support agency are now referring Indigenous patients to the group for assistance although at this stage, figures have not been formally kept about the referral pathways. The group’s reputation has spread through the Aboriginal community in Geraldton and the Midwest-Gascoyne region. Women from the Kimberley region who have heard about the group have visited to learn about its operations. Publicity has occurred through members designing and wearing shirts and stalls at community events, through attendance at meetings and presentations at conferences. IWCSG members reported that local radio and newspaper publicity has also raised awareness of the IWCSG and the need for cancer screening/treatment. The group has developed a logo which it uses on all promotional material which was designed by women from the group (Figure 1).

INSERT FIGURE 1 Logo attached here

Group Effectiveness

Without exception, the health service providers interviewed supported the IWCSG. They acknowledged its role in facilitating Indigenous people’s access to mainstream cancer services, viewing it as a ‘cultural bridge’. They recognised the group’s ability

to communicate in culturally appropriate ways which helped Indigenous women to feel more comfortable with cancer screening and treatment services.

“I think the practical support is huge and the emotional... just being there as a link person to enable them to access different services and transport. I think that is probably one of the biggest things, the most difficult...at the end of the day I am not Indigenous...I will never be able to relate and communicate as well as they can to each other.” [Health service provider]

IWCSG was seen as being better able than non-Aboriginal health service providers to address and manage sensitive issues concerning Aboriginal women’s shyness, need for privacy and shame regarding exposure of body parts. Non-Aboriginal health service providers spoke of their belief that these sensitive areas were better managed by IWCSG members, in part because they were anxious not to offend Aboriginal people yet not confident in culturally safe practice. Aboriginal people could talk about difficult/sensitive issues relating to cancer with other Aboriginal people, whereas this was more difficult coming from a non-Aboriginal person who did not understand the context of an Indigenous person’s life..

“Aboriginal people don’t use services as much...and there are a lot of reasons for that. I think this indigenous women’s cancer support group works really well. Aboriginal people can say things to Aboriginal people that we can’t and often things that aren’t easy to say like ‘get off your butt and get that lump check out’. Like, no other white person could ever say that and not, probably quite rightly, get punched.” [Health service provider]

IWCSG’s capacity to help Aboriginal women overcome their shame of body exposure and fear of cancer screening/treatment via emotional and hands-on support was also highlighted where group members accompanied women to hospital, to screening services and to doctor’s appointments. The group also helped women with cancer with domestic tasks when they were unwell, due to cancer or treatment side effects.

Group benefits

Group benefits were described by the women interviewed who have accessed the IWCSG. They spoke about the emotional support they experienced and the sense of feeling networked into a caring and supportive community which gave hands-on practical assistance to Indigenous people with cancer or carers/relatives. A sense of isolation often followed a diagnosis of cancer and the support and care provided through IWCSG helped to alleviate this. Several participants, both Indigenous women with cancer and carers, described the practical and emotional support they received in domestic crises brought about by the devastating impact of the illness. This included help with cleaning, child care, grocery shopping and even provision of beds/sheets when they were too tired or unable to manage the tasks of daily living due to illness or treatment.

“Coming out of hospital and then coming back to Geraldton where there is no support for Indigenous women, and I didn’t know who to talk to. When I was introduced to the group I just felt like I wanted to cry because this was like a saviour. Like I could talk to them. If I was too sick and I couldn’t clean, they would come and do that too.” [IWSG member]

Carers and relatives who suddenly found themselves responsible for looking after the young children of Indigenous women with cancer similarly accessed practical and emotional support. Participants emphasised feelings of safety and trust while getting help from Aboriginal people and that this encouraged access to treatment and screening services.

Several women who had either previously had cancer or who were currently diagnosed with cancer, spoke about the role of the ‘heart’ in driving the group, where the heart/caring had always been a part of Aboriginal women’s culture, caring for

family and other community members. They said that sharing their story helped them to feel useful in that it helped other women to feel less scared of cancer.

“...yeah the heart, that is probably one of the main things with our lot, reach out...reach out to the next person and do their utmost to help that person and bring her in and get treatment, make sure it is the safe one....It is one of my main things to let people know, help them get over their fear of treatment by telling them my cancer story.” [IWCSG member]

The future: Development of collaborative partnerships

The interface between the IWCSG and health service providers and the need for increased funding were two major issues raised when interviewees were asked about how they envisioned the group's development. With regard to the first issue, a debate arose about whether the group needed to be formalised. Discussion focused on the possible need for a clearly defined role for the group, terms of reference, and policy guidelines, or on whether it would thrive better as a holistic-oriented grassroots organisation. Non-Aboriginal health service providers were concerned about the lack of formalisation and the need for guidelines about the management of clients. On the other hand, Aboriginal interviewees, whether service providers or IWCSG members, indicated that the introduction of structure risks the heart energy of the group, and as such, group disintegration.

With regard to the second issue, to date funding for the group has been rudimentary. Informants reported that a core of founding members have invested many voluntary hours towards the group. IWCSG has now been awarded a further small grant. This will enable the group to operate from a local Aboriginal medical service, and be supported by a part-time group coordinator (0.2 FTE) for two years. The need for ongoing funding for the group and for a full-time coordinator to expand and develop

operations was voiced by IWCSG members and a number of the health service providers interviewed.

Discussion

Preliminary descriptive research with the Midwest IWCSG indicates its potential to facilitate Aboriginal women's access to mainstream cancer screening and treatment services. This bridge between Aboriginal patients and families operates by support for both Aboriginal people and for non-Aboriginal service providers in modelling provision of culturally safe support and care. A cultural strength of IWCSG is its ability to operate confidentially behind the scenes, providing emotional support and practical help directly to Indigenous people concerned about privacy and shame issues. The important cultural role IWCSG plays in overcoming communication and other cultural barriers to accessing cancer treatment was unanimously recognised by health service providers. Aboriginal women supported by IWCSG spoke about an increased sense of safety, trust and support in accessing and navigating mainstream cancer services.

In the year since IWCSG held its first meeting, the group has operated on a combination of small amounts of funding and large amounts of voluntary enthusiasm and energy. A primary issue of concern envisioned by health service providers and group members is the very real possibility of burnout among current volunteers. Acknowledgement of the huge amount of personal time and resources that some members have invested into the group needs to be considered and an arrangement to ensure the sustainability of the group is needed. IWCSG will require ongoing and increased funding to expand and develop its role which is currently limited to fairly

small numbers of people. The need for a full-time coordinator for the group is now critical if it is to maintain and further develop its role. There is also a need for funding for IWCSG to expand its operations to allow regular visits to towns beyond Geraldton including Northampton, Mullewa and Gascoyne, where women have requested support and education from the group. It is also important for the group to develop systems that record more about the occasions of services and nature of assistance provided and for assessment of the outcomes of this support to be carefully evaluated, acknowledging the relatively small number of Aboriginal people in the region. Supporting new partnerships with effective, socio-culturally congruent evaluation models has been highlighted as a primary requirement in forming any successful collaboration.¹⁰

It will be important when the evaluation is completed to address issues concerning further development of effective collaborative partnerships between IWCSG and the health service providers. These include the need to find a comfortable interface between the Aboriginal support group and its holistic culture and aims, and health service providers' concerns about the needs for formalisation and structure. Action research is planned for the future with IWCSG which will look to facilitating this partnership interface and, in so doing, to contribute to much needed evidence-based research about pathways towards forming sustainable engagements in health collaborations between Aboriginal and mainstream health service providers.¹⁰ It is essential for health professionals to develop cross-cultural communication skills to enhance trusting relationships¹⁴. This issue, identified as challenging by both mainstream and the Aboriginal health service and support providers, is perhaps inevitable when the standard model of care is challenged. Yet collaboration in case

management and support could provide a significant opportunity for both Aboriginal IWCSG members and non-Aboriginal health service providers to respectively learn much from each other. Each must recognise the knowledge and expertise that the other brings to the task of supporting Aboriginal people to improve access to cancer screening and treatment and reduce Aboriginal morbidity and mortality from cancer.

Conclusions

Further research with IWCSG is important in that the lessons learnt from the group's ongoing development have the potential to inform a model for setting up similar groups in metropolitan and regional areas with the possibility of adapting the model for a variety of health problem issues. Future research into IWCSG can also contribute to a model for developing effective collaborative partnerships between Indigenous people and non-Aboriginal health service providers.



Figure 1: The Logo of the Midwest Indigenous Women's Cancer Support Group

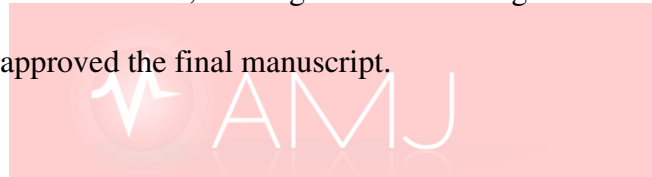
The black around the outside represents black women holding hands, the red represents breasts, the yellow represents the land united from all points (N-S-E and W) and unity is symbolized with the everlasting flower in the centre. The logo means 'Black women united in everlasting care from all corners of the land'.

Competing interests

None.

Authors' contributions

Lisabeth Finn undertook the interviews, analysis and drafted the initial manuscript. Annette Pepper and Pauline Gregory were both involved in establishing IWCSG. They acted as cultural consultants and assistants during the study, advising appropriate cultural approaches to gathering data and arranging interviews with Aboriginal people who had been linked to IWCSG support. Sandra Thompson was involved in the establishment of the Indigenous Women's Support Group (IWCSG), initiating the current evaluation, funding and contributing to drafts of the manuscript. All authors have approved the final manuscript.



Acknowledgements

We acknowledge the participants in this research, all of whom spoke willingly and frankly of the work of this group. We particularly wish to acknowledge the contribution of Shaouli Shahid, Ann Larson, Marisa Gilles, Gail Eliot, Karina Thomason, Pam Haselby, and Terry Brennan for their support in the establishment of this group. The research was funded in part from a grant from The Cancer Council of Western Australia.

References

1. Cunningham J, Rumbold A, Zhang X, Condon J: **Incidence, aetiology, and outcomes of cancer in Indigenous peoples in Australia.** *Lancet* 2008, **9**: 595-595.
2. Condon JR, Armstrong B, Barnes A, Selva-Nayagam S, Elwood M: **Stage at diagnosis and cancer survival of Indigenous Australians in the Northern Territory.** *Med J Aust* 2005, **36**: 498-505.
3. Valery PB, Coory M, Stirling J, Green AC: **Cancer diagnosis, treatment, and survival in Indigenous and non-Indigenous Australians: a matched cohort study.** *Lancet* 2006, **367**: 1842-1848.
4. Coory M, Thompson A, Ganguly I: **Cancer among people living in remote and rural Indigenous communities in Queensland.** *Med J Aust* 2000, **173**: 301-304.
5. Fisher DA, Weeramanthri, TS: **Hospital care for Aboriginals and Torres Strait Islanders: appropriateness and decision making.** *Med J Aust*, 2002, **176**:49-51.
6. Cass A, Lowell A., Christie M, Snelling, P, Flack, M, Marrnganyin B & Brown I: **Sharing the true stories: improving communication between Aboriginal patients and healthcare workers.** *Med J Aust* 2002, **176**: 466-470.
7. Lowell A. **Communication in Aboriginal health care: An overview.** A *CRCATH Indigenous Health and Education Research program review paper.* Casuarina, NT: Cooperative Research Centre for Aboriginal and Tropical Health 1998.

8. Macvean L, White V & Sanson-Fisher R. **One-to-one volunteer support programs for people with cancer: A review of the literature.** *Patient Education Counselling* 2008, **70**: 10-12.
9. Smith K, Humphreys J & Wilson M. **Review article: Addressing the health disadvantage of rural populations. How does epidemiological evidence inform rural health policies and research?** *Aust. J. Rural Health* 2008, **16**: 56-66.
10. Taylor KP, Thompson SC: **Closing the service gap: Exploring collaboration and partnership models between Indigenous and mainstream organizations.** Perth, WA: Aboriginal Alcohol and Drug Service and Centre for International Health, Curtin University, Western Australia. Submitted. 2008.
11. Bishop, B., Vicary, D., Andrews, H. & Pearson, G. **Towards a culturally appropriate mental health research process for Indigenous Australians.** *The Australian Community Psychologist* 2006, **18**: 31-41.
12. Thomas, W. & Bellefeuille, G. **An evidence based formative evaluation of a cross-cultural Aboriginal mental health program in Canada.** *Australian e-Journal for the Advancement of Mental Health*, **5 (3)**. www.ausinet.com/journal/vol5iss3/thomas.pdf.
13. Braun, V., & Clarke, V. **Using thematic analysis in psychology.** *Qualitative Research in Psychology*; **3**: 77-101.
14. Maher P: **A review of 'traditional' Aboriginal health beliefs.** *Aust J Rural Health* 1999; **7**: 229-236.