

# ‘We’ve fallen into the cracks’: Aboriginal women’s experiences with breast cancer through photovoice

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## ‘We’ve fallen into the cracks’: Aboriginal women’s experiences with breast cancer through photovoice

Despite some recognition that Aboriginal women who have experienced breast cancer may have unique health needs, little research has documented the experiences of Aboriginal women from their perspective. Our main objective was to explore and to begin to make visible Aboriginal women’s experiences with breast cancer using the qualitative research technique, photovoice. The research was based in Saskatchewan, Canada and participants were Aboriginal women who had completed breast cancer treatment. Although Aboriginal women cannot be viewed as a homogeneous group, participants indicated two areas of priority for health-care: (i) Aboriginal identity and traditional beliefs, although expressed in diverse ways, are an important dimension of breast cancer experiences and have relevance for health-care; and (ii) there is a need for multidimensional support which addresses larger issues of racism, power and socioeconomic inequality. We draw upon a critical and feminist conception of visuality to interrogate and disrupt the dominant visual terrain (both real and metaphorical) where Aboriginal women are either invisible or visible in disempowering ways. Aboriginal women who have experienced breast cancer must be made visible within health-care in a way that recognizes their experiences situated within the structural context of marginalization through colonial oppression.

**Key words:** Aboriginal women, breast cancer, photovoice, visuality.

This is a crack. It actually goes down to an elevator shaft ... which is what I felt like [was] happening to us. We’ve fallen into the cracks. and nobody can really see ... Nobody really cares because they step over us all the time ... You don’t recognize that this is going on. People walk over; get in and out of this elevator every day. But very few people will look in the crack to see what’s down there or look in there.’ (Sandra, Visualizing Breast Cancer research participant). (Fig. 1)

Aboriginal women’s experiences of breast cancer is best introduced by Sandra who uses the image of an elevator shaft to illustrate that Aboriginal women’s needs and experiences in the healthcare system are largely invisible. Although those involved in health-care, including nurses, increasingly recognize that cancer survivorship is a complex phenomenon, the experiences of Aboriginal women have not been thoroughly addressed. Our research begins to address these

issues and has resulted in the first successful connections fostered between Aboriginal women who have experienced breast cancer, key stakeholders and advocacy groups in Saskatchewan, Canada. These new connections are extremely important to the women and have led to a range of activities geared towards improving support for Aboriginal breast cancer survivors.

Herein we describe our shared exploration of the experiences of work with Aboriginal women through the use of photovoice in a research project entitled Visualizing Breast Cancer: Exploring Aboriginal Women’s Experiences (VBC) (see also Thomas-MacLean, Poudrier and Brooks (2007); Brooks, Poudrier and Thomas-MacLean 2008). The main objective of our work was to explore and make visible Aboriginal women’s experiences of breast cancer through photovoice, a qualitative, participatory and visual research methodology where participants take photographs, are interviewed individually and then participate in a group discussion about collective experiences and needs. Following the

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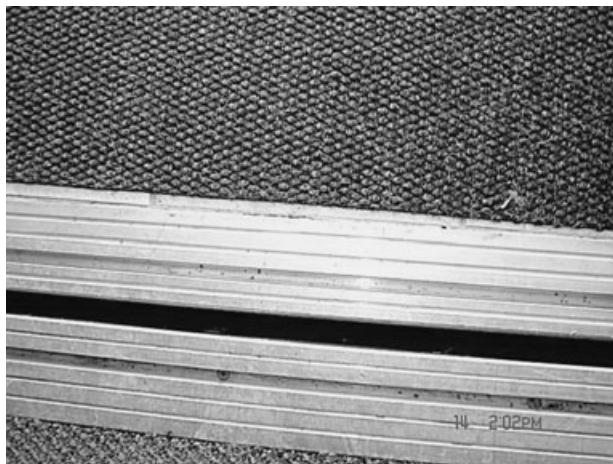


Figure 1 Elevator shaft

participatory action strategy of photovoice, as developed by Wang and Burris (1997), our goals were to work with women: (i) to record their experiences of breast cancer through photography and interviews; (ii) to facilitate discussion among the women about their individual and collective experiences through a sharing circle; and (iii) to develop networks between the women and key breast cancer advocacy and policy groups. To the best of our knowledge, photovoice has not been used in connection with Aboriginal women's experiences with breast cancer. Although there were a number of themes which emerged from the women's discussion of their photographs, this paper focuses specifically on the ways in which their photography and related experiences are connected to health-care. We suggest that Aboriginal women who have experienced breast cancer must be made simultaneously visible both to health professionals including nurses and to newly diagnosed Aboriginal women, in a way that connects their individual experiences with the sociocultural history of colonialism.

## BACKGROUND

### *Cancer experiences*

Psychosocial issues connected to the experience of breast cancer have only recently emerged as an issue of concern to breast cancer researchers (Tomich and Helgeson 2002). The lack of attention to the experience of surviving breast cancer also exists within the domain of ethnicity (Gotay, Holup and Pagano 2002; Ashing et al. 2003), and those researching satisfaction with medical care assert that Aboriginal people's experiences have been neglected (Garroute et al. 2004). Researchers examining the intersection of ethnicity and breast cancer survivorship suggest that

such studies are scant, but that existing research recommends that this is an important dimension that needs attention (Gotay, Holup and Pagano 2002). Furthermore, qualitative research shows that there has been a pervasive, sexist bias in breast cancer research, which has tended to emphasize breast loss, but other issues such as work and disability are more important to women (Thomas-MacLean 2005, 2004a,b). However, this body of research was completed with non-Aboriginal women. It is important to more fully appreciate the similarities and differences between various groups of women, without reification, to begin to establish what their physical and emotional needs might be.

### *Aboriginal women's health*

Research continues to show that Aboriginal people are the least healthy population in Canada, with Aboriginal women experiencing a disproportionate burden of ill-health compared to both Aboriginal men and other Canadian women (Dion Stout, Kipling and Stout 2001; cited in Browne 2007). Many Aboriginal people are located on the margins of the political economy, which is related to their unequal health status and their depiction as the 'other', within health systems (Browne and Fiske 2001; Browne, Smye and Varcoe 2007). Aboriginal people in Canada disproportionately experience the types of health problems associated with lower socioeconomics, poverty, high unemployment and their historical treatment within society (Waldrum, Herring and Young 2006). Incidence of cancer, suicide, chronic illnesses such as tuberculosis and diabetes, respiratory and circulatory diseases are 'much greater' among Aboriginal peoples than non-Aboriginal peoples in Canada. Aboriginal peoples cancer rates are historically low but are increasing dramatically for some cancers and preventable cancers are said to be on the rise (Marrett, Jones and Wishart, 2003). For breast cancer, while Canadian women have a one in eight chance of being diagnosed, the number is higher for Aboriginal women (Status of Women Canada 2005) and survival rates from cancer and breast cancer are lower in Aboriginal populations (Marrett, Jones and Wishart, 2003): 'death rates for First Nations on-reserve people with lung cancer, breast cancer and colorectal cancer are higher than those for the overall Canadian population' (Health Canada 2005, cited in Hannah 2007, 6).

Aboriginal health has been linked to the effect of colonization and neo-colonialism, including a history characterized by wardship, welfare colonialism, displacement of Aboriginal peoples and continued discrimination and racism (Adelson 2005, cited in Browne 2007, 2166). The 1976 Indian Act meant forced assimilation of Aboriginal peoples through

appropriating lands, outlawing spiritual and cultural practices, forced indoctrination into dominant culture through residential schools and forced marginalization onto reserves (Browne 2007). The legacy of residential schools is one of assimilation, loss of traditional Aboriginal culture, displacement and an intergenerational loss of parenting skills (Frideres and Gadacz 2008). Colonization and neo-colonialism has affected all Aboriginal people, but Aboriginal women are said to have experienced the greatest effects (Browne, Smye and Varcoe 2007). Structural barriers and the burden of colonial histories must therefore be considered, when addressing healthcare needs of Aboriginal women who experience breast cancer.

### ***Research with Aboriginal women***

As it relates to research with Aboriginal women, innovative nurse scholars in Canada have advocated for an interdisciplinary approach to health-care, suggesting that disciplines outside the health professions may offer a great deal to the shaping of healthcare policy and practice. For example, Fiske and Browne (2006) use critical discourse theory to analyse the paradoxical ways in which Aboriginal women are simultaneously constructed as both 'empowered citizens' and 'discredited medical subjects' in healthcare policy (91). Browne and Smye (2002) draw upon postcolonial theory to address how healthcare discourses tend to ignore the complex connection between health and health-care and the legacy of colonial power and history, thereby perpetuating 'negative stereotypical images of Aboriginal women' and their health as problem of individual lifestyle or a matter of cultural difference (28).

Smye and Browne (2002, 47) draw upon the general concept of 'cultural safety' used in New Zealand to reveal the social construction of Aboriginal peoples in Canadian healthcare contexts in a way that is connected to the socio-historical and political marginalization of Aboriginal peoples through neocolonial oppression. In their qualitative research with First Nations women in northwestern Canada, Browne and Fiske (2001) show the ways in which women's encounters with healthcare services are experienced as 'invalidating' and 'affirming' (126). Invalidating encounters were exemplified by women's narratives of feeling dismissed by healthcare providers, experiencing negative stereotypes of First Nations women, feeling vulnerable and others. Meanwhile, affirming encounters were characterized by such things as the ability to actively participate in healthcare decisions through respectful communication, the affirmation of personal and cultural identity and the development of positive, long-term relationships (Browne and Fiske

2001). In exploring these narratives, Browne and Fiske (2001) argue that it is essential to see Aboriginal peoples not just as individuals, but in ways connected to the structural and pervasive legacy of colonial oppression and marginalization.

It is important that Aboriginal women's health is continuously envisioned as connected to individual experience and the structural issues of colonialism. We suggest that these ideas can be further developed through the feminist and critical concept of visuality as connected to empowerment and marginalization.

### ***Feminist visuality***

With a similar metaphor of the visual and the use of lenses, the sociological imagination as originally articulated by C Wright Mills (1959) offers a similar promise of imagining through world by continuously linking the complex relationships between personal experience and social structure. In essence, it draws connections between personal troubles as public issues (Mills 1959). Contemporary scholarship with a focus on visual imagery and its connection to power is exemplified in feminist theory (Clarke and Olesen 1999; Haraway 1999, 2001; Martin 1999) which asks us to interrogate the dominant visual terrain where we see problematic images of marginalized women. Visuality, as the act of seeing and interpreting is a political and power-laden process of communicating knowledge and perspective. Several critical feminist scholars suggest that we live in a cultural context which increasingly operates through visual imagery as key form of power which is understudied (Mirzeoff 1998; Martin 1999; Haraway 2001; Sturken and Cartwright 2001). Where what constitutes visual reality in dominant discourses is simply a reflection of the perspective of advantaged communities, it is more important to understand the visual perspectives of those most marginalized (Haraway 1999). Indeed, some scholars further argue that one way to work towards any form of social equality in the broader social context is to privilege the visual perspectives and the voice of those most marginalized from power/knowledge discourses, particularly women of colour (Haraway 1999), and in this case Aboriginal women. It is these women who have the most objective vantage point — from the outside of the dominant discursive terrain.

In the context of visual research in health, Harrison (2002) suggests that imagery in photography for example, can be seen as 'ways of telling, stressing the particular experiences, views and situations of the subject/author' (858). Furthermore, visual images can act as a force that has a transformative potential (Pink 2001). Where pictures may be worth a thousand words, images captured by marginalized

persons explained through a story can have potential for sociocultural and policy change. Where the neocolonial discourse in health-care holds a problematic image of Aboriginal women (Fiske and Browne 2006), photovoice can refract the colonial gaze by asking women to reveal the world as seen through their eyes. As such, research in the visual, with a view to refract the colonial gaze through the women's photography, is a useful orientation for illuminating the lived experience of Aboriginal women who have had breast cancer in empowering ways.

## METHODOLOGY AND METHOD

### *Decolonizing methodologies*

Decolonizing approaches to research are focused on privileging the knowledge, philosophies and needs of indigenous peoples. Tuhiwai Smith (1999) argues that globally indigenous peoples have been over-studied or victims of problematic research processes and findings, thus a decolonized approach to doing research is necessary. Tuhiwai Smith (1999) explains that decolonizing research should begin by putting indigenous world views at the core of any indigenous projects. Moreover, from a Foucauldian perspective, she suggests that indigenous peoples can move from positions of marginalization to powerful spaces of critique, resistance and development.

In decolonizing research, it is crucial to develop research methodologies that see indigenous knowledge, experiences, values and experiences in the centre of the research. Our work was aimed at shifting research participants from their role in previous research as 'the other' or 'passive victims' studied by outsiders, to empowered activists within their own communities. Understanding the experiences of breast cancer requires a philosophical position where researchers work with Aboriginal women to reflect upon their own experiences and communities and to develop strategies for transformation that are likely to be more effective in the local context. In order to do so, with a group or community of women that had not yet been established, we did not rely on a strict research agenda tied to a finely detailed conceptual framework. Instead, we worked with loosely structured theoretical concepts such as visuality and power. In doing so, our priority was to facilitate collaboration and trust with the women and in a way that values their expertise.

### *Photovoice*

Photovoice, developed by Wang and Burris (1997), is a participatory method where researchers work with marginalized

communities to better understand individual and community health concerns. Photovoice prioritizes participants' knowledge as a vital source of expertise, with 'the possibility of perceiving their world from the viewpoint of the people who live lives that are different from those traditionally in control of the means for imagining the world' (Ruby 1991, 50). In these ways, power inequalities may be addressed by investing participants with the authority and responsibility to define important issues in their lives, as is congruent with feminist and critical approaches to as resistance (Brown and Strega 2005). The process can facilitate the reclamation of indigenous knowledge, which is a critical component of health and healing for indigenous peoples (Smith 1999; Moffitt and Robinson 2004).

As such, the main objective of our work was to explore and to make visible Aboriginal women's experiences of breast cancer. Following the photovoice technique (Wang and Burris 1997), our secondary goals were to work with Aboriginal women '(i) to record and reflect their personal and community strengths and concerns, (ii) to promote critical dialogue and knowledge about personal and community issues through group discussions of photographs, and (iii) to reach policy-makers' (185).

### *Setting and recruitment*

In 2004, approximately, 610 Saskatchewan women were newly diagnosed with breast cancer. (Canadian Cancer Society 2005). There are two major urban areas in this western province — Regina and Saskatoon — which are similar in size, with populations of approximately 225 000 people. Eight participants lived in urban areas, while the remaining participants lived within a 300-km range of the two major urban centres.

Aboriginal organizations, universities, a cancer centre and Breast Cancer Action Saskatchewan distributed information about the research. Articles about VBC study appeared in Saskatoon. A Métis elder, who wishes to remain anonymous, also provided guidance during the study design and wrote a newspaper article in a local Aboriginal publication in support of the study. Interestingly, but not surprisingly, it was this appearance of this article which was the key factor in recruiting women. Recruitment criteria were (i) 19 years of age or older, (ii) completed active breast cancer treatment at least 6 months before our study, (iii) be able to provide informed consent, (iv) reside in Saskatchewan, and (v) identify as Aboriginal. Reimbursement for participation was \$75 for three stages (two interviews and photography) of data collection.

## Participants and design

In total, 15 women began as participants in the project and three did not complete the study for personal reasons. However, 12 women completed the study and ranged in ages from 42 to 75. Three of the women lived in urban areas in Saskatchewan while the remainder lived in rural towns or in First Nations communities. Several of the women were grandmothers and all were mothers to children of a range of ages.

At the first meeting, participants were asked to share their story of having had cancer and these stories were digitally audiotaped. Participants then borrowed the digital cameras for several weeks. The women were asked to take any number of pictures their experience of breast cancer meant to them, with the suggestion that 12–15 photographs would be sufficient.

During the second digitally recorded interview, the women were asked to discuss the photos and to provide a description of what the photo was meant to convey. They were also asked to select and discuss several photos that they felt were especially meaningful to them. It was these selections that began the thematic analysis of the research. This second interview was also digitally recorded and the photos were saved to the laptop computer. Overall, this data consisted of 24 interview transcripts and over 150 photographs.

In a following 1-day event, the women came together in a morning sharing circle to share their photographs and stories in a safe and comfortable environment. In the afternoon, key stakeholders from advocacy groups including the Saskatoon Health Region, Breast Health Centre, Breast Cancer Action Saskatchewan and Breast Cancer Community of Stakeholders were invited to join us in a workshop to discuss forming new networks this new group of women. This process is further described and analysis of its benefits for working with Aboriginal women is further explored elsewhere (Brooks, Poudrier and Thomas-MacLean 2008).

## Ethics

With attention to the decolonizing research philosophies (Smith 1999), our ethics guidelines followed principles outlined in the *Canadian Institute of Health Research (CIHR) Guidelines for health research involving Aboriginal people* (CIHR 2007). We followed the guidelines proposed by Schnarch (2004) in 'ownership, control, access and possession' where the women's photography is viewed as their own. We also followed the *Ethical guidelines for Aboriginal women's health research* prepared by the Prairie Women's Health Centre for Excellence (PWHCE; 2004). With respect

to the consenting aspects of the photovoice, we followed ethics outlined by Wang and Redwood-Jones (2001). Numerous researchers (e.g. Smith 1999; Brown and Strega 2005; Poudrier 2007) have highlighted the ways in which ethical concerns are not simply a set of procedures to be followed with respect to the review process, but a means of epistemologically framing the research itself in indigenous contexts. Our overall philosophy of research was respecting indigenous knowledge and the views of the women. Although we received ethics approval from our institution's Research Ethics Board before data collection, we re-applied for ethics approval as indicated by the requests of the women. For example, while we originally intended to de-identify people in the photographs, the women wished to be visible in their photos.

## Interpretation

The participating women provided the initial and most important interpretations of the photos and discussed key themes extensively during the second interviews. The women were asked to describe the meaning of the photographs and to choose those which were most significant to them. Extensive team discussions, as well as review of the transcripts and photos then guided the interpretive processes, which always drew upon the participants' own words and indications of what was meaningful to them. Our theoretical framework, in the domains of feminist epistemology with a focus on visibility and power, provided filters through which we collectively interpreted and thematized the stories and photos. Additional guidance for the analysis came from various writings on the use of visual methods in sociology. For example, Wright (as cited in Riley and Manias 2003) outlines three processes involved with the interpretation of photos:

looking through the image to information internal to it; looking at the image to examine the way in which the content is presented; and looking behind the image to examine the context, or the social and cultural relationship that shape its production and interpretation. (85)

Rigor regarding the development of the themes was ensured first, by independent coding by the three researchers, second, with extensive team discussions surrounding the development of the themes, and finally, with the Aboriginal women in a sharing circle following the individual interviews. Finally, participants were asked to provide feedback on this research process. All of the participants expressed the idea that they benefited individually and relationally from the research. They spoke of enjoying the creative process as a chance for self-reflection. Relationships also developed

between the participants. In words of the women: 'This was a great way to tell my story;' 'This photo project was a wonderful, wonderful exercise;' and 'This project has changed my life — you women have changed my life.'

## FINDINGS

Based on the theoretical traditions previously outlined, one key aspect of this research was a clear focus on understanding the women's experiences as connected to broader issues of racism and colonialism without reifying Aboriginal women's position as homogenous demographic (and often pathologized and powerless) category. Indeed, although Aboriginal women may share life stories, even when they are from the same province, their experiences may be decidedly different. This point was clearly articulated here by Marion: 'there are so many First Nation's people, [with] different languages, different cultures. Although there [are] a lot of similarities, there's some great differences too.'

In what follows, we highlight Aboriginal women's photographs based on their experience of breast cancer in terms of their own healing and as connected to their experiences with those involved in health-care. Two key interrelated ideas around health-care include: (i) Aboriginal identity and traditional beliefs, although expressed in diverse ways, are an important but not very well understood dimension of breast cancer experience, and (ii) there is a need to address the larger sociological issue of racism, power and socioeconomic inequality. In essence, the women felt that their experiences and needs — indeed they themselves — must be made visible to those involved in health-care and to newly diagnosed women. The need for Aboriginal women to be visible is introduced by Sandra, whose words appear at the beginning of this article. Indeed, Sandra very creatively and powerfully uses a picture of an elevator shaft to illustrate this invisibility as Aboriginal women as those who have 'fallen into the cracks'.

### *Spirituality and Aboriginal identity in the experience of breast cancer*

One main theme that emerged as was the important role of Aboriginal identity and traditional spiritual beliefs in the experience of breast cancer. Several women located their traditional spiritual values and practices at the centre of their experience of breast cancer. Others described a spiritual approach which blended Aboriginal teachings with Christian values. Yet other women suggested that traditional values, medicines or teachings played no part in their lives or in their recovery from breast cancer.



**Figure 2** Dorothy's braid

As a woman who was closely connected with Cree spirituality, Dorothy suggested that one of the most difficult aspects of breast cancer was the loss of her hair. According to her father, the cutting of hair would signify the death of someone or mourning in the loss of a loved one. As such, she had never cut her hair. She said: 'the only time that, people cut their hair is when they lost loved ones, and that's what I believe today.... When I lost my hair, I cried. I cried. "Well now, maybe I'm gonna die" I said to myself.' Once she began to lose her hair and her braid was cut, her husband smudged the braid and prayed (fig. 2).

Although the loss of hair during chemotherapy may be generally viewed as a major event for anyone experiencing cancer, the significance of Dorothy's hair loss was not only linked to aesthetics and femininity, but also more deeply connected to the fear of death and loss, associated with her cultural beliefs.

Other participants discussed the role of traditional practices in healing such as prayer, the use of the sweat lodge, smudging and traditional teachers. For example, both Mary and Shelley spoke about breast cancer as linked to healing. Mary described her use of the sweat lodge alongside the use of rocks as a form of energy and recovery from breast cancer:

The rocks are very important in my life and they are used in the sweat lodge. When we go into the sweat lodge, they're the ones that are heated up and they're the ones that take away all your sickness. So then we call them grandfathers, sometimes when you hold a rock you will feel healing energy from it. And I have lots of rocks in my apartment like I've got rocks all around me, and they give you energy. (Fig. 3)

Shelley, who identified as a Métis woman and had recently re-connected to her family's cultural values and traditional practices, took a photo of her family sweat lodge explaining that it was a salient part of her recovery from breast cancer. For her, it was a source of connection to traditional values and family and a source of strength. The sweat lodge was also seen as a safe place for healing — a place free of racism:



Figure 3 Mary's rocks



Figure 4 Shelley's sweat lodge

The sweat lodge ceremony is a big part of my life and that's where I did most of my healing ... Anything and everything in there is safe. Everything in there is equal because when that door is closed its black. So nobody, there's no color. There's no racism in there. There is nothing in there. It's really like a positive experience. (Fig. 4)

Some participants suggested that while they did not follow traditional spiritual practices, they did relate to shared Aboriginal experiences such as residential schooling. For example, Marjorie lived in residential schools as a child and was raised with predominantly conservative values and Christian religious beliefs. Although her experiences of residential school were extremely negative, she also saw them as a source of strength and survival — of resilience. She felt that if she was strong enough to survive residential school, she was strong enough to beat cancer: 'what [the residential school] tried to beat down in me, brought something up that's been hidden right along and brought it up and I'm a better person for it.'



Figure 5 Marie's shrine



Figure 6 Tina and her doctor

In another example, while Marie's spiritual faith was also an important part of her experience of breast cancer, it was predominantly based in Christian values. She described a shrine she had built as being very important to hear healing process:

This is my shrine. The second time I had cancer I decided to put that up. I go and pray in there. I have holy water right beside there ... there are ashes there from my husband's brother in law. The priest has come there and blessed the holy place. (Fig. 5)

In a different example, Tina's connection to her identity was also shaped by her experiences of foster care. Coming from a background of poverty and abuse, at 8 years old she was placed in foster care in a relatively wealthy non-Aboriginal home. She states:

So, I went through a real identity crisis, to the point where I hated Indian people. I thought 'well, is that what they

meant to me is that they were abusive, alcoholics and poverty? I didn't want that and it wasn't until I was in my late thirties that I realized that I don't mind being an Indian.

When discussing her own Aboriginal identity in more specific terms, Tina explains: 'I don't really have anything ... I may be that color, but that's about it. I have no culture. I have no desire to learn it ... but I am accepting of it.' At the same time, however, Tina sees a strong need to make Aboriginal women's needs visible to healthcare practitioners.

On the other hand, some women did not have any association with Aboriginal cultural or shared identity. Cheryl, who was born and raised in a First Nations community, stated that she did not really 'identify that way'. She felt some tensions around claiming an Aboriginal identity in the context of our project because she strongly felt that breast cancer was simply a woman's disease and experience, no matter her ethnicity.

Based on the photos and the related stories of the women, it was clear that identity, tradition and spirituality were at the centre of the experience of breast cancer for some of the women in our group. It would then be important for those involved in health-care to understand the importance of traditional beliefs and values in their healing. In the case of Dorothy's braid, for example, it would be very important for healthcare providers to have an awareness that the experience of hair loss is may be profoundly frightening for some Aboriginal women and that it may also be linked to the uptake of chemotherapy and western medicines generally.

Based on the women's insights, we see some profound interconnections between the women's personal experiences of healing from breast cancer and the socio-historical legacy of colonization including: the abuse of residential schooling, the experience of being adopted into non-Aboriginal families, the movement from traditional spirituality into Christian-based religions, the movement back to practicing traditional medicine and the resounding resilience of Aboriginal women. Moreover, as we see in Shelley's words, there are concerns around racism and the need to find a safe space for healing — one that was free of colour, inequality and racism. As such, it was felt that those involved in health-care become familiar with the complexity of Aboriginal women's lives, but also their connection to the larger sociological problems linked to the marginalization of Aboriginal women.

### *Multidimensional support*

Although we have explored the concept of support in a previous article (Thomas-MacLean, Poudrier and Brooks 2007), it was largely within the context of young Aboriginal women's experiences and the many demands on their lives

(e.g. conflicts between paid work, illness and raising children). Here, we examine more closely, the implications of racism for health-care and support systems. Underpinning all of our VBC work is the process of making visible that which has been otherwise ignored, neglected or not understood by the healthcare system and support groups. The significance of support for Aboriginal women in cancer diagnosis and treatment is revealed by Marion who stated that 'it's so important for Native women to have that support. It is. You see so many people out there dying of cancer because they don't have support.' We see the previous discussion around the importance of values, spirituality and Aboriginal identity as a powerful force in the background. Although these needs may not be unique to Aboriginal women, here we bring into focus the women's ideas, problems and solutions regarding health-care. Overall, they suggested that their needs have been relatively invisible and could be made visible through (i) Aboriginal women's support services; (ii) respectful communicative strategies with healthcare professionals; and (iii) the ongoing availability of information that is relevant to their lived experiences.

### **SUPPORT GROUPS AND SERVICES**

One resounding theme that emerged very quickly in our discussions with the women was the fact that existing breast cancer support groups did not necessarily meet their needs. In several cases, women did not have any access to support groups because of their more remote location. In other cases, where women were able to access them, they did not find support groups helpful because they did not reflect their lived realities and left them feeling marginalized. This feeling of marginalization was connected to identity, cultural values, experiences and socioeconomic position. Sandra shared her experiences as a participant in a breast cancer support group. In reference to her relationship with the women, she stated that 'although we have a common disease, we don't have common lifestyles'.

However, at least one woman had very positive experiences with breast cancer support groups and continued to participate in their activities. Cheryl was heavily involved in an exercise group for women with breast cancer and felt that support was really about individual experience and attitude, rather than connections to Aboriginal identities and experience.

Most participants suggested that having support mechanisms that reflected the realities of Aboriginal women would have been helpful. Marjorie, along with others, further indicated that it would be important to have an Aboriginal women's support group. Likewise, Tina felt that it would have been helpful simply to see other Aboriginal people

while going through treatment: 'I looked around for any ... I couldn't find any like me out there... I couldn't see any brown faces... I would have loved to see another brown face in there.'

The overwhelming sentiment of women was that it would be important to see an Aboriginal person in a supportive healthcare role. The role of Aboriginal identity and the complexity of experience played a significant role in the discussions about supportive environments and breast cancer survivor support groups. Moreover, almost all of the women talked about support for Aboriginal women in a two-dimensional way: they felt it was important to have support groups for Aboriginal women or those which reflected their lived realities; and they felt strongly about offering that support Aboriginal women, or men, who are newly diagnosed with cancer. The women's commitment to supporting others has been described more extensively in a previous manuscript (Thomas-MacLean, Poudrier, and Brooks 2007) and concrete initiatives in this regard are currently underway. Importantly here, the women linked the current invisibility of Aboriginal women in support group settings to both their lived personal realities and the broader social inequalities and marginalization experienced by Aboriginal peoples.

#### SUPPORT FROM HEALTHCARE PROFESSIONALS

In many cases, the women suggested that the role of healthcare professionals through the style of communication was important. Similar to the findings of Browne and Fiske (2001), we see a range of medical encounters which are both affirming (the ability to actively participate in healthcare decisions through respectful communication, the affirmation of personal and cultural identity and the development of positive, long-term relationships), and invalidating (experiences of racism, dismissal, vulnerability and a lack of understanding).

Marion discussed her relationship with her oncologist suggesting that a straightforward and respectful communication style was very important and played a role in her own resiliency through breast cancer:

I remember this one time when I went this year. I was telling her 'I'm scared. I know I'm gonna die,' and she said 'Marion, you're not gonna die.' Like you know, she was just really straightforward and she wouldn't treat me like a baby. She would tell me all the way that 'You have to be a fighter.' She would tell me 'You have to stand up for yourself, because nobody else is gonna do it. Nobody else is gonna take chemo for you. You gotta do it yourself.' She was just an amazing woman.

Tina, as the only woman who took a picture of a healthcare professional, discussed her positive relationship with one of her physicians: 'She is a very nice lady — very, very

nice. She was open and honest with me and she went through all of my tests with me.' Tina also describes her own role in establishing a respectful communication pattern:

The only time that I had to get vocal with her was one day. I usually don't lose, um, get aggressive with anybody. But this time, I did. [My doctor wanted a procedure done] and I just said no! and I said, 'I don't know how many times I have to say this.' ... 'I have made my decision and I don't want to go through the rest of my life with things that I may regret. It's my decision, my body.' She's never mentioned it ever again. Never. So, I like her. (Fig. 6)

Alternatively, many women described invalidating encounters through racist comments made by healthcare workers. In this example, Marjorie described a situation as a young cancer patient in her 30s going to chemotherapy. At the clinic, she noticed that the majority of those receiving chemotherapy were much older than she was and were non-Aboriginal. She talked about how her unique position as communicated through a nurse played out as implicitly racist:

The nurses could be very patronizing ... Not taking anything away from them. They were good at their jobs. They were good nurses ... When they get to me, it's like 'Gee that's kind of hard on you huh? We don't really see your kind in here none too much.' ... and then I asked that lady, 'Well what kind would that be? Elaborate please. Could you tell me what kind that is? Give me the concept or the thought behind what you've said.' ... She was a training nurse. She got me so aggravated and I thought 'Girl, you insult all blondes.' I was so fucking pissed off.

In communicating with healthcare professionals, Marjorie reveals tensions between the notion of expressing sympathy and identifying her uniqueness, but perhaps in a context with little understanding about the complexity of racially based communications. These types of encounters were also experienced by other women. Although these experiences may not be unique to only Aboriginal women, we highlight these as important themes for the Aboriginal women in our group.

With these examples that convey the range of experiences, the women overwhelmingly felt that their relationships with healthcare professionals were important in two areas: (i) understanding Aboriginal women's lived experiences, and (ii) communicating in ways that are supportive, straightforward and reflect some sensitivity to racism.

#### SUPPORTIVE INFORMATION

In a final interconnected theme related to multidimensional support, it was evident that women needed information that was relevant to their lived reality. Many of the women indicated that the information that they received did not match their socioeconomic situation. For example, Marion



Figure 7 Library

suggested that it would be important to know how to access support services for low-income women:

I had no money. A lot of Native people can't afford the stuff that you need. Prosthetics are about four to five hundred dollars. They're really expensive and I couldn't afford that. Here in Regina, McIntyre Street, there's a building where you could get the stuff for free. And back then I never knew that. Nobody told me about that.

Again, this idea is a reflection of Sandra's previous discussion about support through breast cancer groups and the need to recognize that some Aboriginal women may be living in poverty. Here Marion conveys the idea that, it is important to ensure that specific information is provided very clearly to women with low incomes.

Many women also felt that it was important to have information that was communicated in an accessible fashion. Sandra stated: 'The surgeon who speaks to you, the doctors, the medicines you're taking — the words they use are commonplace in their daily life. But in ours, they're not.' (Figs 7 and 8)

Many women indicated that they did not always understand what was being explained and they did not seek clarification for fear of looking unintelligent. Sandra felt that it was important to be able to ask questions after an appointment:

You know, and maybe you don't want to ask questions and then you go home and you're stuck now because, who do you ask? I like the whole [nurse] navigator idea where you have that person or somebody that comes with you that can understand, but a lot of times we don't have that somebody.

In summary, many of the women suggested that their needs were relatively invisible and that it would be helpful to have support that was relevant to their lived experience. Relevant support could take the form of (i) support groups specifically for Aboriginal women; (ii) respectful communication strategies with healthcare professionals; (iii) and the ongoing availability of information that is relevant to their lived experiences. These forms of multidimensional support

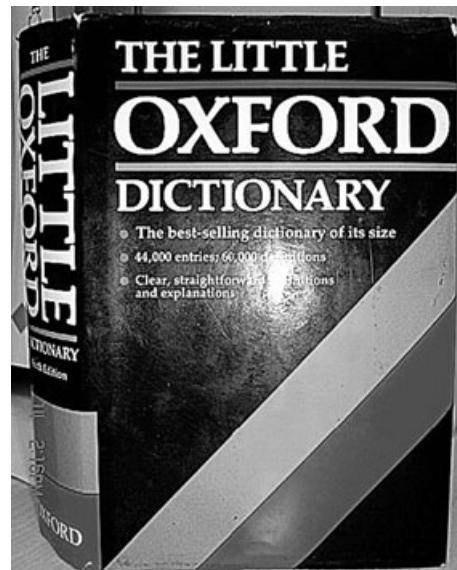


Figure 8 Dictionary

may be valuable, empowering or affirming (Browne and Fiske 2001). They are intended to reveal the complexity of Aboriginal women's lived experience as linked to the broader sociological context.

## IMPLICATIONS

Where Aboriginal women who have experienced breast cancer have been largely invisible, our work with them through the research technique, photovoice, was intended to explore and represent these perspectives visually. We were also able to meet our other objectives including facilitating a connection among the women and also with key stakeholder groups. We draw from the interrelated concepts of visuality, which sees images as sites of power and resistance which requires us to see Aboriginal peoples' experiences in health-care settings and policy discourse as inextricably bound to its socio-historical structural roots in colonial oppression and marginalization.

Our findings include two interrelated themes regarding health-care. First, Aboriginal identity and traditional beliefs, although expressed in diverse ways, are an important but not very well understood dimension of breast cancer experience. It would then be important for those involved in health-care to understand the importance of traditional beliefs and values in their healing. For example, the meaning of hair loss may be profound for some women and this meaning could have linkages to treatment. Healthcare professionals will need to be aware that Aboriginal women may have unique spiritual needs and perhaps offering opportunities to discuss these issues in clinical and other healthcare settings.

Second, there is a need for multidimensional support which reflects, and makes visible, the lived realities of Aboriginal women in three areas: (i) Aboriginal women's support systems; (ii) respectful encounters with healthcare professionals; and (iii) the ongoing availability of information that recognizes their socio-historical and structural position in the context of colonial marginalization. Specific strategies suggested by the women included an Aboriginal nurse navigator and information and support designed specifically for newly diagnosed Aboriginal women. This type of affirming multidimensional support in health-care would then simultaneously recognize Aboriginal women's differential experiences and needs.

The more tangible implications of this work have been the success of networks established between the women and advocacy group alongside their collaborative initiatives aimed at developing multidimensional support mechanisms and making the women's experiences visible. Since the conclusion of our research, for example, there have been a number of initiatives including; a second sharing circle with the participant women and other women to more firmly develop plans with Breast Cancer Action Saskatchewan; the development of the new Aboriginal Women's Breast Cancer Advisory Committee for Saskatchewan<sup>1</sup>; the fostering of connections and information to Breast Cancer Screening Program in Saskatchewan to better develop programmes to support Aboriginal women; the dissemination of information about the Visualizing Breast Cancer project and the women's experiences through posters at the events 'Living with Cancer' and 'Connecting the Breast Cancer Community' held in Saskatoon; and other plans to develop support materials for newly diagnosed women, particularly those living in remote areas.

Although we cannot be certain what implications these initiatives will have for healthcare systems, we would suggest that there is a great momentum and commitment to making Aboriginal women's experiences of breast cancer visible, both broadly and in healthcare contexts. We and others see an incredible strength and creativity in the women and their photography. We expect that these powerful images linked with ongoing initiatives will convey the Aboriginal women's strength and diversity. We also expect that these powerful visual representations will begin to disrupt and transform

the current representations of Aboriginal women with breast cancer as powerless and vulnerable — or simply invisible in healthcare settings.

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<sup>1</sup> The meetings to facilitate the development of this group was sponsored by The Saskatchewan Breast Cancer Network. This is a Canadian Breast Cancer Initiative, Public Health Agency of Canada which is hosted by the Canadian Cancer Society funded towards community capacity building. The network's purpose is to increase awareness, information and support for those concerned with breast cancer and breast health.

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