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Abstract
This manuscript is a reaction to the high prevalence of breast cancer amongst Aboriginal women. Our work calls for more attention to the effects of race, gender, and class on cancer fears and related experiences. The shock of a cancer diagnosis and fears of recurrence can leave patients feeling that their lives are out of control. Combining the visual method of photovoice with focus groups and in-depth interviews, we develop an understanding of cancer experiences that includes fears related to: socio-economic realities; supporting families both emotionally and financially; environmental concerns, especially those that arise from living on reserve; race and racism; and cultural beliefs. Breast cancer experiences are shown to be significantly linked to history and the impact of colonization, neo-colonialism and point to the importance of a postcolonial feminist framework and cancer support policies informed by a lens of cultural safety.

Key Words Aboriginal women, breast cancer, cultural safety, fear, photovoice

Visually depicting cancer fears: Beyond biomedical concerns

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Introduction

Breast cancer is the most common and invasive cancer amongst women and the second largest cause of cancer-related death.[1] A Canadian woman's risk of developing the disease in her lifetime is approximately one in nine.[2] Survival rates have increased with advances in treatment and cancer detection3-4; the breast cancer death rate in Canada is currently the lowest it has been since 1950.[2] Although Canadian cancer registries collect limited statistical data across different racial groups,[5] the incidence of breast cancer appears to be rising more quickly in Aboriginal (Métis, Inuit, and First Nations)[6 p.xi] versus non-Aboriginal women[1] and survival rates are also poorer[7]. First Nations women have a higher likelihood of being diagnosed at a later stage of breast cancer and worse diagnoses.[8] Racial/ethnic disparities in surviving cancer are higher in breast cancers and other cancers that can be detected early and successfully treated.[9]

Despite increased survival rates in the general population breast cancer fear and distress are pervasive.[10-11] Moreover there is a lack of research with Aboriginal people on their medical care satisfaction[12] and the effect of ethnicity on cancer experiences and associated fears.[13-15] Cancer care and survivorship experiences may be heavily influenced by race, gender, and class,[5,16] yet experiential research is scarce,[17-19] and fears have not been explored from the perspective of Aboriginal women. The few studies that have been done reveal cultural silences with respect to cancer: "Speaking about cancer brings negativity … I am not sure if it's not the breast I don't think it's the breast thing I think it is a culture thing, we don't want to hear it."[20]

This manuscript is a reaction to the prevalence of breast cancer in Aboriginal women and the calls for more research into the effect of race, gender, and class on cancer care and cancer experience.[14,17-18] Our aim was to develop a contextual understanding of the meaning of breast cancer for Aboriginal breast cancer survivors.

Theoretical framework

Social epidemiological considerations

Links between social, economic, and political forces and social determinants related to health outcomes and services are increasingly recognized as important yet remain marginalized in debates on health policy and in health literature.[21] Knowledge of these links provides an initial lens through which to understand the stories of Aboriginal breast cancer survivors. Aboriginal peoples continue to suffer social and economic inequalities that are linked to histories of cultural genocide and colonization. Although social problems have been linked to this historical trauma the relationship with physical health is not as consistently understood. Failure to address these underlying social forces has led to inadequate explanatory frameworks.[22]

Much of the Canadian literature on class, socio-economics, and breast cancer is epidemiological.[5,23] A Canadian survey distributed to breast cancer survivors revealed that 50% endured a period of financial need during their treatment and diagnosis; the loss of income had a more profound impact on women with lower socio-economic status.[24] Other research suggests that mortality rates due to breast cancer are higher for lower-income women.[25,26] Mackillop et al. note that women with household incomes <$20,000 have a 5-year survival rate of 64%; this rate is substantially lower than 76% for women with household incomes >$50,000.[27] In addition the overall increase in rates of survival mask worsening rates for some groups (e.g. African American women in the United States and Aboriginal women in Canada) associated with access to protective measures, knowledge, preventive health care, self-esteem, environmental exposure, occupational exposure, early detection (in the case of breast cancer), and access to quality medical care.[28] While cancer rates among Aboriginal peoples are historically low, rates for some cancers in some regions are increasing dramatically.[29] Survival rates from cancer and breast cancer are also lower in Aboriginal populations.[7]

Aboriginal health scholars increasingly argue that socio-economic and income inequality has important consequences for the well-being and health of Aboriginal people, especially women and children.[30] Some of the highest poverty rates in Canada are amongst Aboriginal peoples.[31,32] According to the Canadian Center for Policy Alternatives, "[n]ot only has the legacy of colonialism left Aboriginal peoples disproportionately ranked among the poorest of Canadians … disturbing levels of income inequality persist as well."[32 p.3] Many Aboriginal people also suffer from insecure living situations. Problems with housing include severe overcrowding, disrepair, and a lack of basic necessities and are associated with negative consequences for health.[33] Other related problems are a lack of income for quality foods and difficulty accessing medical services and consumer goods.[34]

Social epidemiology combines economic with social inequalities when considering the health of ethnic minorities.[35] Social inequalities include discrimination, perceptions of discrimination, and racial harassment, which are identified as markers of stress that increase negative outcomes of disease.[35] Social epidemiological researchers commonly define social justice within individual, risk-based frameworks. Prescriptions for social justice often lie in enabling disenfranchised and marginalized peoples to adopt healthier behaviours.[36] However, some social epidemiological work more readily addresses structural variables that are also detrimental to peoples' choices and health.[35] This ongoing work draws on a more structural approach in an attempt to identify "un-healthful forces" that are linked to unequal health outcomes.[36 p.465] This epidemiological work calls for intervention strategies to reduce disparities,[9] which we argue draw attention to the importance of including a postcolonial feminist and culturally safe lens.

Post-colonial feminist theories

Post-colonial feminists recognize intersections of race, class, and gender as well as women's agency and subjectivity,[36] arguing that it is essential to begin with the standpoint of the oppressed and hear voices that have been lost.[38,39] Important to postcolonial feminist scholars are concerns related to colonialism, neo-colonialism and the continued impact on people's lives.[38-39]

Postcolonial feminists have transformative social change as their goal. Postcolonial feminists illuminate connections between gendered positioning with class and racialization while acknowledging colonial histories, neo-colonialism, and effects on choices, and opportunities:[40-41]

Racism and sexism found in the colonial process have served to dramatically undermine the place and value of women in Aboriginal cultures, leaving us vulnerable both within and outside of our communities…the tentacles of colonization are not only extant today, but may also be multiplying and encircling Native peoples in ever-tighter grips of landlessness and marginalization, hence, of anger, anomie, and violence, in which women are the more obvious victims.[42 p.128-9]

Postcolonial feminist theorists aim to address social determinants of health including historical determinants formed through colonialism and neo-colonialist relations. Health inequalities are illuminated through a critical gaze informed by an understanding of women's experiences and contextualized in the wider political, social, economic, and historical context. The 1876 Indian Act, for example, meant forced assimilation of First Nations peoples through appropriating lands, outlawing spiritual and cultural practices, forced indoctrination into dominant culture through residential schools, and forced marginalization onto reserves.46 First Nations women who married non-Status Indian men or non-Indian men prior to 1985 also lost their status and rights/protection.[46] This affected their ability to own property, contributed to increased rates of poverty, and resulted in poorer heath.43 Some scholars argue that colonization "provides a context for understanding why the age-standardized mortality rate for all causes among First Nations women is substantially higher compared to other Canadian women".[42 p.131]

Postcolonial feminists ask why Aboriginal women are more susceptible to certain health risks yet also warn that assumptions about class, cultural, and racialized identities creates/reinforces difference, Othering, and culturalism.[44] Through the continued effects of colonizing and neo-colonial practices Aboriginal women have often been identified as an 'inferior' and 'subordinate Other'.[44] The process of Othering means that stereotypical (and racialized) assumptions of identity, culture, and difference are not reflective of actual identities. In addition theories that draw attention to specific racial groups risk 'culturalism', or cultural essentialism. Cultural essentialism can result from well-intentioned efforts to attend to differences within cultures. For example, Narayan,[42] describes how many women from 'Third World' cultures are essentialized based on the most underprivileged. Similarly, Canadian research must caution against glossing over heterogeneity and linking Aboriginal 'culture' with social problems related to poverty, dependency, addiction, and poor health.[42,45]

The problem of culturalism and Othering also applies to the interpretation of health statistics and indicators. Profiles of health and statistics alert communities to important trends regarding health and illness. However, there are important risks associated with reporting trends without the context of social, economic, and historic determinants. The wider determinants of health evident in the intersection of class, culture, racialization, historical subjugation, and gender are easily overlooked in favour of blaming individuals and groups of people/cultures for lifestyles associated with ill-health.[45]

Postcolonial feminist scholars introduces the concept of 'cultural safety' as a lens that simultaneously views individuals in their location and in relation to colonial marginalization.47 Cultural safety is often used as a lens for health care workers to "think critically" about themselves and to be "mindful of [their] own sociocultural, economic, and historical location" and how this affects their work with marginalized patients.[44] Cultural safety may reveal "taken for granted processes and practices that continue to marginalize Aboriginal women's voices and needs".[44] Here we use cultural safety to analyze the women's words and pictures within their location, related to colonization; and encourage healthcare providers to do the same. Cultural safety encourages researchers, policy makers, and health care workers to ensure that the effect of history, especially colonization, is understood when addressing Aboriginal women's health concerns.[45] This does not mean simply being sensitive to cultural differences or specific needs but acknowledging inequalities and the effects of colonization and neo-colonialism, and moving beyond sensitivity to an analysis of power and discrimination.[48] Colonization has resulted in a combination of oppression by race, gender, and class, and therefore any analysis of breast cancer experience for Aboriginal women should be layered and undertaken within a de-colonizing framework. Decolonizing research cannot be divorced from colonial histories and privileges the voices of indigenous people and offers an avenue towards empowered resistance.[49]

Methods

We used photovoice, a qualitative research method, to collect stories from Aboriginal women breast cancer survivors. Photovoice is a participatory visual method in which participants take photographs to capture their perspectives.[51,52] Current research suggests that photography may be a creative and empowering way to better understand the experiences of populations that have been marginalized, such as Aboriginal women.[50]

Photovoice, which has connections to feminist epistemology, visual knowledge and power literature, is a research tool that allows research participants to tell their stories and assess their needs visually.[51,52] Using a combination of photography, interviews and focus groups, photovoice is used to empower people to "1) to record and reflect their personal and community strengths and concerns, 2) to promote critical dialogue and knowledge about personal and community issues through group discussions of photographs, and 3) to reach policy makers".[53] While photovoice has been used in ways congruent with our research, to the best of our knowledge it had not been used to explore the meaning of breast cancer and Aboriginal health.

Following this method our research used a combination of photography alongside focus groups and in-depth interviews.[53] We recruited 14 participants through First Nations and mainstream news and posters in cancer centers, support centers, and Aboriginal agencies but two withdrew due to time constraints. The remaining 12 participants represented rural, urban, and on-reserve locations in Saskatchewan. The initial focus group provided an opportunity for the women to share their stories collectively and to be invited to take pictures of their experiences. Because the recruitment process was difficult we had three different focus groups, occurring in the first three months of the study. Participants then took photographs over a period of several months and participated in one, two or three in-depth interviews until they were satisfied that they had relayed their experience fully. Many of the women felt that they wanted to take more pictures to visually relay additional themes and experiences that came up in their one-on-one interviews. There was one final focus group at the end of the study with all of the participants and interested community stakeholders. Overall the data for this study consisted of over 28 interview transcripts and 200 photographs, with the women involved over a period of 14 months.

In the interviews and final focus group the women directed their interviews with reference to their pictures and we encouraged the conversation to move from personal stories to social analysis and possible social and policy changes. Most of our participants moved to social analysis without specific questions. The photographs allowed the women to direct the discussions and reflections. The final focus group held at the end of the project was an additional opportunity for critical dialogue among the research team, participants, and breast cancer stakeholders concerning the women's shared experiences and reflections on how to enhance cancer care. Stakeholders included those representing the Breast Cancer Screening Program of Saskatchewan, the Saskatoon Health Region, Breast Health Center, Breast Cancer Action Saskatchewan and the Breast Cancer Community of Stakeholders.

The picture taking by the women participants involved time, reflection, emotion, motivation, risk, and uncertainty, and resulted in creativity, depth, enjoyment, and relationship building. For example, Shelley noted that "This was a powerful exercise, I really liked it…helped me set priorities…what is important to me." Unexpectedly, all of the participants did not wish their pictures or transcripts to remain anonymous; they preferred to be credited openly for their contributions because they felt this would help other women survivors and other Aboriginal women experiencing cancer. This speaks to the participants' engagement with this method as well as their willingness to share their lives to assist others. We recognized the participants' rights to be identified if they wished—especially because of the participatory nature of this research and amended the ethics application. We developed a revised consent form, designed to ensure that participants had a choice regarding their anonymity. To ensure participatory analysis of the data, as researchers we continued to see ourselves as learners not "experts". We used a grounded theory approach, which allowed our research team to discover what participants were telling us rather than to assume a pre-given knowledge.[54,55]

Our participants took pictures to document their realities and engage in critical reflection both individually and in group processes using their images and stories to advocate community and policy changes.[56] During the interviews and focus groups the women were themselves moved to discuss immediate fear of cancer, fear of recurrence, as well as the social context of their lives. This is understood as a benefit of this research method.[57] Through photovoice, participants are empowered to represent and also enhance their communities through the documentation of their life experience through photography.[53] Community members are thereby offered an opportunity to assist in the development of relevant policies.[53,56]

Limitations of the study include time-constraints and cultural protocols. For example, a number of women shared that they could not take pictures of natural medicines, Sweat Lodges, Sun Dance or other ceremonies, because they are sacred. Another limitation concerns the connection of photovoice to social policy. Minkler,58 for example, asks whether a focus on participant's contribution towards enhancing their lives and others may take away from broader community responsibilities and cast social problems as individual problems.

Although the women showed resilience and strength and reacted positively to the methodology, fear was the most predominant feeling expressed.

Results

Fear

While the women in our study showed strength and profound resilience, fear also persist. The women spoke of the fear associated with diagnosis noting that this fear was devastating and often linked to dying. Marion said that she never thought that cancer would happen to her and was totally devastated, linking it to death; "…all I thought about was death…and I realized that after a while, like, it's not necessarily a death sentence." Sandra associated fear with dying and describes feeling a fear more powerful than any that she had ever experienced:

> …I've been afraid of… when… you think your babies not breathing and your heart stops.... You know my mom died and my divorce fell apart.... I have never been that afraid in my life.

The participants' words also craft powerful imagery of spinning, being wounded, and feeling isolated. Sandra talked about feeling as though she had no control over the direction of her life:

> [It was like]…somebody had blindfolded me and spun me in circles and then took them off and wanted me to find my way…And I couldn't do it because I had no idea which direction I was going.

Fear of cancer recurrence (FCR)

The fear that plagued many of the women participants upon first diagnosis persisted throughout their treatments and after they were declared in remission. Fear of cancer recurrence (FCR), defined as a concern of cancer returning, metastasising, or progressing, was also common.[59-61] Many talked about how everyday occurrences, such as developing a cold-sore, or having a sore throat, became a source of fear. Sandra said that her first explanation for anything different that she experiences is always cancer:

> Like I count my freckles and my spots and I feel them….whenever something happens… the first thing that comes to my mind is cancer.

Using winter and herself in a tipi as a metaphor, Sandra talked about FCR. For her, standing in the bare tipi symbolized feeling exposed to cancer—even though she has been in remission:

> …I wanted to take this because it's like, winter, everything's sleeping…that's how I feel about the cancer inside of me too… That it's still sleeping. And I feel very exposed, all the time.

See Figure 1: Exposed

Fear of racism and othering

Sandra described a number of things about the picture of herself in the tipi (above) over and above her fear of cancer recurrence. The image also represents her exposure to false and harmful generalizations and her fear of being stigmatized. She explains,

> This one… the tipi…it's a skeleton, the skins are missing, so I'm exposed …You see the past…and the present. That's me inside of there. I'm trying to hide, but I'm not hiding…you can very much see. You can see that I'm an Indian, for me, I can see that.

Cheryl connected financial stresses to her experience as an Aboriginal woman and also talked about being wrongly defined through racial terms. She experienced discriminatory treatment when dealing with government programs when cancer left her unemployed. She went to her Member of Legislative Assembly, Member of Parliament, and the newspaper (Saskatoon Star Phoenix) to deal with how she had been treated through the welfare system, community resources and services. She said the questions she was asked about her Aboriginal heritage made it clear to her that she was being treated unfairly:

Figure 1 – Exposed

> They asked me if I was Aboriginal, and I thought, "Yes", and I was going to ask the interviewer, "And what nationality are you?" Like what difference does it make?... And then she asked me when I last lived on the reserve? And I thought, "What does that have to do with my breast cancer?"

Marjorie's experiences with a health care professional reveal the complexity of what it means to be sensitive to 'race' in health care communications. Marjorie recalled an interaction with one of the nursing staff:

> The nurses could be very patronizing…Not taking anything away from them. They were good at their jobs. … When one training nurse got to me, [she's] like: "…That's [Cancer is] kind of hard on you?... We don't really see your kind".

Marjorie then talked about how this affected her:

> And then I asked that lady, "Well, what kind would that be? Elaborate please. Could you tell me what kind that is?…She was a training nurse. She got me …I was so… pissed off.

The women also talked about fears related to Aboriginal women's silence being misinterpreted. Marion spoke of her own experience and how silence was learned in her childhood at day school:

> I wasn't in residential school, I was in day school, but the teachers were totally mean and I learned to be silent. Because I used to always get hit…I was just afraid…then I realized I couldn't ask anybody to go through cancer for me. I had to do it myself. That was the hardest thing for me, was staying strong.

Sandra expressed how silence is a reaction to racism and being responded to in certain ways, noting that this builds over time:

> I also know what it feels like to just recoil, because you're so accustomed to people looking at you and saying things to you a certain way that you don't even want to hear it anymore, or feel it anymore. So you [are afraid to] ask questions. I don't put my hand up in school because I didn't want them to think I was stupid.

She continued on to link her history with her fear of asking questions and associated problems during treatment.

> In the same way, you know, I can see that we don't want to ask questions or appear too stupid you know, maybe you don't even know what a bilateral mastectomy is.
>
> If your doctor's telling you…you have these options of a lumpectomy or a mastectomy or a blah blah, I mean, you might not have a clue what he's talking about….and maybe you don't want to ask questions and then you go home and you're stuck now because, who do you ask?

Sandra talked about her own life situation and being silenced over time. She said that she was given the strength to speak out and felt it was her responsibility to speak for those who were not offered that same privilege. Similarly Marion expressed wanting to be there for other Native women because she recognizes their fear, lack of trust and shy disposition:

> …why I would like to be there for other Native women is because [of the] way, the way Native women are… A lot of Native women are really shy. Like…most Native women don't trust easily.

Marion added that problems with drugs and alcohol were linked to fear and avoidance for some women on her reserve. Marion talked about the difficulties she had talking with women who were dealing with addictions and cancer:

> She doesn't really like to talk about…her experience with breast cancer. Like she's been through…drugs and alcohol a lot, like everyday. So, she doesn't really talk about it…when I was first diagnosed … she had finished her chemo, this lady… from the same reserve I am…and … I was so scared back then, but, but there was just no talking to her because … she has such a different lifestyle.

All of the women agreed on the importance of health care and other professionals being sensitive to women's fears related to racism and stereotypes; this was extended to understanding certain behaviours within the context of colonial histories. The women were concerned for themselves and other Aboriginal women not asking questions or not going for treatments because of deeply engrained silences and lack of

Figure 2 – Praying at Work

trust embedded within colonial histories.

Socio-economic fears

Financial concerns also weighed heavily. Sandra shared that she often felt the "weight of the world" on her shoulders. She expressed this with a visual image of her praying at work:

> Yeah, and that was me on my knees at work. Just kind of praying. You know, Lord please let me make it through this day, let me keep my job so I can feed my children, let me just help me. You know cause a lot of times I don't know where I'm gonna get help from and, I feel the weight of the world on my, on my shoulders …

See Figure 2: Praying at work

Cheryl indicated that the fear of losing her source of income and the limitations of Canadian employment insurance were more difficult than ongoing cancer treatments. She had her Employment Insurance cut off, was declined by the Canada Protection Plan, and Community resources all within two weeks:

> So that was a bigger fear than going through the [cancer] treatments…The treatments were a piece of cake compared to [finances].

Cheryl's situation made her wonder what would have happened if not for the kindness and gifts from her rural community and, moreover, what would happen to other women whose communities do not so readily respond to the needs of their members. Cheryl included a photo documenting how her community held two fundraisers for her after she lost her Employment Insurance.

See Figure 3: Support

Sandra recalled an incident where she needed to buy a breast surgery support bra, but could not afford it. She explains that another woman in her support group offered to buy her the bra:

> Like I need the bra and I can't afford it. One woman says "Well I'll buy you a bra". And I said well thank you but you're not really getting my message here. I said, "what? [Are you] gonna buy us all bras?"

With respect to social problems related to class or race the women talked about how this was often misrepresented by de-contextualizing a social problem and viewing this as an individual problem.

Fears related to social and environmental problems

The women participants who lacked resources and were on social assistance when they were receiving treatments also talked about not being able to afford certain recommended foods. Their stories included information about other First Nations women who live on reserves, who they felt shared fears related to social and environmental problems, including food availability, crisis in communities, and violence:

> …I mean you can't tell somebody who lives up in like, Fond du…[where it costs] like twelve dollars for milk or… how do you tell these women to eat properly? …I mean we're just gonna have to, you know maybe not focus so much on the diet, I mean, even lifestyle is a tough one… (Sandra)

Dorothy moved to Saskatoon, leaving her home and reserve during her treatments because of the poor living conditions. She described the housing and the surrounding environment and discussed why it was so important for her to move into the city. Below she talks about the picture of her wood stove, which is her only source of heat for the cold Saskatchewan winters:

> …my house has never been renovated since it was new. And I'm living in that house... And that's my heat, for winter time … a wood … the same thing … fifteen years…. I've been asking for them to buy me a new stove.

See Figure 4: Housing

Dorothy saw a connection between cancer and the environment, the water, and unused community facilities. Like many of the women she spoke not only out of concern

Figure 3 – Support

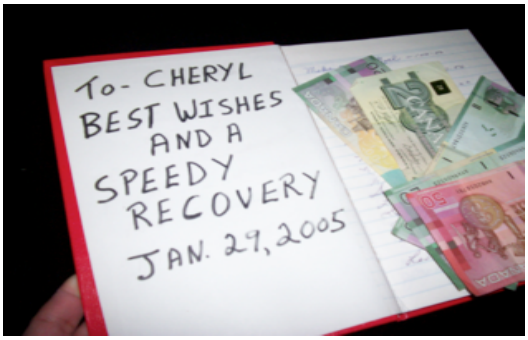

Figure 4 – Housing

for her own welfare:

> …the water's…I think it's maybe contaminating some place… And there's a lot of deaths…And that's what…really bothers me.

See Figure 5: On-reserve

Not every community is set up with health centers and medical professionals and the participants spoke about how far many women have to travel for appointments and for treatment:

> … it's hard on the reserve, I mean you're miles from anywhere, how do you get there? Unless somebody picks you up… not every community has a nurse. Or a health center…you know a lot of them are taking medical taxis into the cities…to their appointments or whatever… (Sandra)

Conditions on the reserves and in isolated communities were less than ideal for early detection and screening or for healing from breast cancer. Individuals with access to proper housing, nutritious foods, clean water and accessible health information are better able to use resources and prevent illness.[36] For the women, early detection and screening is associated with access to knowledge, preventive health care, self-esteem, and access to quality medial care. The women's fears related to cancer were often about how their environment would impact their healing and how cancer may worsen existing social problems.

Culturally-specific fears

The impact of cultural norms and beliefs about bodies, health, and cancer also affected women's fear and approach to their own health. Seven of the women shared that it was common on the reserve for women to avoid discussing cancer, doing self-examinations, and going to doctors or even treatments once diagnosed. Marion, Sandra, and Mary talked about women they continued to worry about. Mary said that,

> a lot of Indian women just turn around and, don't even bother to even complete their treatments because, they're scared and there's nobody there to give them encouragement and support.

Figure 5 – On-reserve

Sandra spoke of a woman whose cancer became visible on the outside of her body, yet still did not seek treatment:

> …her breast started seeping and she still didn't go to the doctor. I mean amazing, amazing. I don't know why, but she just didn't. In fact, you know people talked about her, that, that smell of it even and she just, well she ended up passing away of course but, I think um, how do we reach those women?

Sandra talked about her experience and her shock at an Elder who had never checked her breasts in 75 years:

> I just kind of asked them sitting around, you know would you be interested in…an afternoon session on breast cancer …and alot of interest. So when we did a poster I took it to the Elder and asked her about it. And for the first time, she checked her breast. For the first time in like seventy-five frickin' years the woman checked her breast.

Dorothy talked about the impact of her culture on her hair loss. She was taught that when people cut their hair, they lose a loved one and, therefore, losing her hair held great significance. Before it fell out due to the cancer treatments, she cut her long (never been cut) braided hair and brought it back home to her husband:

See Figure 6: When I Lost My Hair I Cried

Dorothy recalled that "…when I lost my hair, I cried. I cried", and this led to her believe that "[w]ell now, maybe I'm gonna die…".

Many of the women also discussed beliefs about cancer held by members of their families or communities, especially when they were from a reserve community. The women shared stories of family members who could not look at them or talk to them while they were going through cancer. This was connected to a belief that "[c]ancer is very contagious and that people always die from cancer" (Marion). The women explained how certain First Nations traditions and culturally-specific fears were sometimes linked to resistance to go for breast cancer screening or to seek treatment. This was a recurring theme, as an Elder participant told us to remember that many Aboriginal people feel that they cannot

Figure 6 – When I lost my hair I cried

acknowledge a lump for fear of welcoming cancer into their bodies, noting in her own experience that "[w]hen I found my lump... I didn't want to invite it". This was also mentioned by Marjorie, who noted a prevalent beliefs is "[i]f you touched yourself you invite the cancer into your body". Sandra felt similarly and afraid of surgery when she found her lump:

> I don't wanna call it a myth, but… I've been told by many people that you shouldn't …be cut… have surgery because it will spread the cancer. So there's a lot of… myth out there. (Sandra)

In fear for other Aboriginal women, Mary spoke of cultures that believe that if they are treated by "white man's medicine" that their medicines will no longer work. If they are very traditional people, the women asked, how do they "move forward with any type of treatment"? Sandra agreed,

> You know it might be that, they, they go so far that they can't be helped, you know? By the time they realize…they may be hospitalized and then there's not much that can be done anymore.

A few participants indicated that some cultural and/or community-based assumptions may be one reason that Aboriginal women in isolated communities are not being diagnosed earlier and are reluctant to go to the doctor when they do find a lump. All of the women expressed deep concerns about women living in more isolated communities and the impact of reserve living.

Discussion

The women's stories and visual images reinforce the impact of social forces on cancer-related experiences and well-being. Although the women expressed fear of cancer and recurrence their fears were very much related to lived realities. The findings that emerged during data collection and analysis recognizes prominent social forces that impact the psychological well-being and fear of participants: cancer fears related to race (racism), class (socio-economics), gender (conditions of being an Aboriginal woman), and culture and history (colonization).

Our findings reinforce conclusions from the socio-oncology literature with respect to feelings of fear.62-63 For example, "[t]he shock of hearing that they have a cancer diagnosis leaves many patients feeling "wounded" and "out of control".[63 p.15] Other common feelings include isolation and a fragile sense of inner well-being.[63] There is also a very strong fear associated with cancer diagnosis as well as fear of recurrence, which may lessen over time but does not surcease.[77] FCR is discussed in the medical literature as being almost universal, persisting for many years after cancer treatments are finished.65 With respect to breast cancer, 22 to 99% of survivors experience FCR.[66-68] Because more people are surviving breast cancer due to treatment advances, many more women are now living with the risk and persistent fear of the disease returning. Problems with anxiety and distress are common among cancer patients, with recent studies reporting over 65% of cancer survivors experience depression.[69]

There is an abundance of literature on breast cancer, including longitudinal studies that demonstrate the distress, fear, and disruptions that occur.[61,70-75] Demographic factors such as age and type of cancer diagnosis are recognised as relevant to fear, distress, and FCR. For example, age is consistently noted as a factor related to FCR,[59] with older breast cancer survivors often found to have less FCR than younger counterparts.[61,76-79] However, less common in the literature are links between the psychological experiences of fear and their association with culture, class, gender, and race.[80] No consistent associations have been found between FCR and gender, ethnicity, or education. In their comprehensive search Crist and Grunfeld[59] only found three studies that demonstrate an effect of ethnicity; two studies demonstrating higher rates of fear amongst African-American versus Caucasion survivors[59,78] and one identifying higher levels of fear and FCR in Latino women.[78]

Although our purpose here is not to speak to correlations between fear and ethnicity, we suggest that literature on fear may need to shift or broaden its focus to understanding the meaning of fear. Our qualitative and visual work speaks to a furthered understanding of the type of fear that affects Aboriginal women. The fears of the women in this study included those associated with racism/discrimination, poverty, and family crisis, and were often culturally specific. The words of our participants point to the importance of services for Aboriginal women with breast cancer that focus on the real issues—poverty, violence, nutrition, isolation—and an understanding of the impact of racism and the effect this has on experiences of fear:

> I think that programs …when they're dealing with Aboriginal people, they need to be realistic and look at the issues that are really facing them…whether it's poverty or abusive relationships or FAS [fetal alcohol syndrome] …there is all of these other things that … [are] very prevalent in First Nation societies. (Sandra)

Moreover, our findings concur with research that shows a need to develop more experiential knowledge of women who suffer social problems related to economic and racial barriers.[81] The intention of our research was to learn from the pictures and survivorship experiences of Aboriginal women in Saskatchewan, and to make their voices and images more visible. The analytical framework that evolved shows the importance of the social context of coping with cancer treatment and survivorship. Findings show how fear and feelings of helplessness/being out of control are influenced by socio-economic realities, such as losing one's job or not having access to resources such as healthy foods or information; supporting families both emotionally and financially; environmental concerns, especially those that arise from living on reserve; and race and racism. These discoveries highlight the need for policies, healthcare practices and research to identify survivorship in the complexity of lived experience, contextualized by interconnections of race, class, and gender. Socio-oncological, epidemiological and medical research and health practitioners may also benefit from including a postcolonial feminist analysis and culturally safe lens. Cultural safety may be used as a lens for health care workers to critically reflect on the link between Aboriginal women's experiences of cancer and inequalities and institutional discrimination that resulted from colonization and to critically reflect on their own health care practice.[44,48] In this way, cultural safety is also a tool which allows health care professionals and researchers to question how their beliefs and their treatment of Indigenous peoples may be embedded in colonial power relationships.

A number of very ambitious directives evolve from these findings. Understanding Aboriginal women's resistance to going for early detection or treatment may help health care professionals become more sensitive to the specific needs and fears of these women. For example, understanding Dorothy's fear of losing her hair may allow health professionals to recognize the importance of including Aboriginal traditional and spiritual practices alongside mainstream practices. Understanding cultural fears or appreciating that different communities may have historically grounded beliefs, allows health care professionals to approach communities differently. For example, Marion suggested information with images and information relevant to communities be made available, with pictures of Aboriginal women speaking directly to fears and to resilience. To this end, four posters with images from this study have already been created and provided to breast cancer support and prevention networks. Medical and nursing practice may also benefit from consideration of Aboriginal women's fear that cancer may worsen poverty, isolation, and increase racism. We contend that it is important for health care professionals to be aware of systemic barriers to health care, especially given the very real repercussions of racist stigmatization as well as racial and class inequalities.

The women's words also point to the importance of support services within health care geared specifically to meet the needs of Aboriginal women. An advisory network led by Aboriginal women may help to raise awareness of fears and lived realities. To this end, the services provided by Native Liaison workers could be expanded.

The role of a Native Liaison Worker is to provide links between the health care center and Aboriginal peoples. Part of their service is to support Aboriginal peoples undergoing treatment, to increase understanding of cultural practices and beliefs. However, the women in our study called for more inclusive materials recognizing not only cultural beliefs but also cultural and regional heterogeneity, language barriers, ongoing colonial experiences, and survivor stories of Aboriginal peoples. This is especially important because many Aboriginal women may not ask for support or speak out because they have been silenced.

It is our position that the Aboriginal women's stories of fear and of their lives must be understood in the context of colonial histories using a lens of cultural safety.[44,48] This means that educational materials, health care support, and Native Liaison services must be framed with an understanding of the ways that colonization has resulted in oppression by race, gender, and class.

Lastly, our findings suggest that photovoice is an empowering methodology suitable for conducting health research with Aboriginal peoples—especially considering deep concerns about the historical link between colonization and a population that may feel they have "been researched to death."[82] Identifying Aboriginal women's breast cancer survivorship concerns from their perspective contributes to knowledge about Aboriginal healing and health in a way that privileges experiential voices and respects diversity.

Conclusion

This manuscript addresses how cancer fear is more than individual qualities, cultural sensitivities, and biomedical concerns. The participants have created individual, relational, historical, social, and political analysis. Their words link fear to broader, structural issues, including experiences of systemic racism, colonial histories, structural inequalities, and environmental and social determinants. The images and information gained may provide direction for increased levels of support as well as more inclusive materials for health care professionals and breast cancer patients that recognize spiritual customs, traditional medicine, cultural and regional heterogeneity, and anecdotal stories of survivors. Our concern is that this work and the voices and pictures will stop there. These Aboriginal women's experiences of breast cancer are stories of social injustice and social control, and the voices and visual images lead to questions of substantive equality between subgroups in society. The women addressed links between racism, socio-economic inequalities, environmental concerns, and the impact of colonial policies on illness and health inequalities. Their support needs, survivorship stories, and resiliency were contextualized with consideration of the intersection of gender, race, age, class, and culture. We cannot define race, age, or gender as important determinants of health without also acknowledging the intersection of these social spaces, their impact on people's lives, and heterogeneous and diverse ways of coping, survival, and living.

Experiential approaches to breast cancer83, 23 are often critical and place women's experiences within a broader social and political situated context. Although there is a call to add the effect of race on cancer experience and survivorship,14,19 we argue that rather than simply add 'race', research must continue to develop the importance of understanding interconnections of social contextual forces that affect women's lives. A lens of cultural safety means that we draw continual attention to how Aboriginal women survivors of breast cancer are influenced by the context and history of their lives but survive differently—have power, resilience, strength, pain, and struggles.

> I don't call myself a survivor I call myself a warrior…
> I don't feel I have survived it yet. I have daughters
> and granddaughters.
> I don't have the …medical knowledge, but we are so
> much more than science
> …This provides me an opportunity to help my
> daughters and perhaps your daughters. (Sandra)

References

1.Canadian Cancer Society. Breast cancer statistics. 2005. Available from URL: http://www.swc-cfc.gc.ca/pubs/b5_factsheets/b5/factsheets_7_e.pdf. Accessed 13 Nov 2008.

2.Breast Cancer Society of Canada. Breast cancer statistics. 2013. Available from URL: http://www.bcsc.ca/p/46/1/105/t/. Accessed 17 Nov 2013.

3.Canadian Breast Cancer Foundation. Breast Cancer Statistics. 2013. Available from URL: http://www.cbcf.org/central/AboutBreastCancerMain/AboutBreastCancer/Pages/BreastCancerinCanada.aspx. Accessed 5 Dec 2013.

4.Clegg LX, Li FP, Hankey BF, Chu K, Edwards BK. Cancer Survival among US whites and minorities: A SEER (Surveillance, Epidemiology, and End Results) program population-based study. Archives of Internal Medicine 2002; 162:1985-993.

5.Wilkinson S. Breast cancer: Lived experience and feminist action. In: Morrow M, Hankivsky O, Varcoe C (eds). Women's health in Canada: Critical perspectives on theory and policy. Toronto: University of Toronto Press, 2007; 124-41.

6.Waldram J, Herring A, Young T. Aboriginal health in Canada: Historical, cultural and epidemiological perspectives. 2nd ed. Toronto, Buffalo and London: University of Toronto Press, 2006.

7.Marrett L, Jones CR, Wishart, K. First Nations cancer research & surveillance priorities for Canada: Workshop report. Cancer Care Ontario, 2004. Available from http://www.cancercare.on.ca/documentsw/ACSFirstNationsWorkshopReport.pdf. Accessed 19 Aug 2008.

8.Cancer Care Ontario. Diagnosis of breast cancer occurs at a later stage among First Nations women in Ontario. Jun 2010. Available from URL: http://www.cancercare.on.ca/english/ocs/snapshot/ont-cancer-facts/. Accessed 5 Dec 2013.

9.Tehranifar, Parisa, Alfred Neugut, Jo C. Phelan, Bruce G. Link, Yuyan Liao, Manisha Desai and Mary Beth Terry. 2009. "Medical Advances and Racial/Ethnic Disparities in Cancer Survival". Cancer Epidemiology, Biomarkers and Prevention 18: 2701.

10.Vahdaninia M, Omidvari S, Montazeri A. What do predict anxiety and depression in breast cancer patients? A follow-up study. Social Psychiatry and Psychiatric Epidemiology 2010;45(3):355-61.

11.Ando N, Iwamitsu Y, Kuranami M, Okazaki S, Nakatani Y, Yamamoto K, Watanabe M, Miyaoka H. Predictors of psychological distress after diagnosis in breast cancer patients and patients with benign breast problems. Psychosomatics 2011;52(1):56-64.

12.Garroutte EM, Kunovich RM, Jacobsen C, Goldberg J. Patient satisfaction and ethnic identity among American Indian older adults. Social Science and Medicine 2004; 59: 2233-44.

13.Ashing KT, Padilla G, Tejero J, Kagawa-Singer M. Understanding the breast cancer experience of Asian American women. Psycho-Oncology 2003; 12(1):38-58.

14.Lopez EDS, Eng E, Randall-David E, Robinson N. Quality-of-life concerns of African American breast cancer survivors within rural North Carolina: Blending the techniques of photovoice and grounded theory. Qualitative Health Research 2005a; 15(1):99-114.

15.Chlebowski RT, Chen Z, Anderson GL, Rohan T, Aragaki A, Lane D, Dolan NC, Paskett ED, McTiernan A, Hubbell FA, Adams-Campbell LL, Prentice R. Ethnicity and breast cancer: factors influencing differences in incidence and outcome. Journal of the National Cancer Institute 2005; 97(6):439-48.

16.Hewitt M, Breen N, Devesa S. Cancer prevalence and survivorship issues: Analysis of the 1992 National Health Interview Survey. Journal of the National Cancer Institute 1999; 91(17):1480-6.

17.Gill T, Feinstein AR. A critical appraisal of the quality of quality of life measurements. Journal of the American Medical Association 1994; 272:619-26.

18.Leedham B, Ganz P. Psychosocial concerns and quality of life in breast cancer survivors. Cancer Investigation 1999; 17(5):342-8.

19.Lopez EDS, Eng E, Robinson N, Wang CC. Photovoice as a community-based participatory research method: A case study with African American breast cancer survivors in rural Eastern North Carolina. In: Israel BA, Eng E, Schultz AJ, Parker EA (eds). Methods in community-based participatory research for health. San Francisco, CA: Jossey-Bass, 2005b; 326-348.

20.Mitchell TL, Burhansstipanov L, Baker E, and St. Germain Small M. (Advisory Group). Power point presentation on the Aboriginal women's cancer care project at Halifax, 8-12 June 2005.

21.Bolaria BS. Sociology, medicine, health and illness: An overview. In: Bolaria BS, Dickinson H (eds). Health, illness, and health care in Canada. 4th ed. Toronto: Nelson Education Ltd., 2009; 123-41.

22.Mitchell TL, Maracle D. Healing the generations: Post-traumatic stress and the health status of the Canadian Aboriginal population. Journal of Aboriginal Health 2005; 1(2):14-23.

23.Thomas-MacLean R. Beyond dichotomies of health and illness: Life after breast cancer. Nursing Inquiry 2005; 12(3): 200-9.

24.Kasper AS. Barriers and burdens: Poor women face breast cancer. Breast cancer: Society shapes an epidemic. In: Kasper, A.S., Ferguson, S.J. (eds). Breast cancer: Society shapes an epidemic. New York: St. Martin's Press, 2000; 183-212.

25.Lannin D, Mathews H, Mitchell J, Swanson M, Swanson F, Edwards M. Influence of socioeconomic and cultural factors on racial differences in late-stage presentation of breast cancer. Journal of American Medical Association 1998; 279:1801-7.

26.Macleod U, Ross S, Gillis C, McConnachie A, Twelves C, Watt C. Socio-economic deprivation and stage of disease at presentation in women with breast cancer. Annals of Oncology 2000;11:105-7.

27.Mackillop W, Zhang-Salomons J, Groome P, Paszat L, Holowaty E. Socioeconomic status and cancer survival in Ontario. Journal of Clinical Oncology 1997; 15(4):1680-9.

28.Hannah R. Primary prevention of cancer in Aboriginal communities. 2007. www.awhhrg.ca/resources/documents/PrimaryPreventionofCancerinAboriginalCommunities.pdf. Accessed 19 Aug 2008.

29.Cancer Care Ontario. Colorectal cancer increasing in Ontario First Nations people. 2005. Available from URL: https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=13140

30.Frideres JS. Overcoming hurdles: Health care and Aboriginal people. In: B.S. Bolaria BS, Dickinson H (eds). Health, illness, and health care in Canada, 4th ed. Toronto: Nelson Education Ltd., 2009; 183-203.

31.Ross DP, Scott KJ. Smith, P.J. The Canadian Fact Book on Poverty. Canadian Council on Social Development. Ottawa, Ontario, 2000.

32.Wilson D, Macdonald D. The income gap between Aboriginal peoples and the rest of Canada. April, 2010. Canadian Center for Policy Alternatives. 2010. Available from URL: http://www.policyalternatives.ca/sites/default/files/uploads/publications/reports/docs/Aboriginal%20Income%20Gap.pdf. Accessed 20 Nov 2013.

33.Durbin, A. Caanda's response to the on-reserve housing crisis: A study of the Kelowna Accord. Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health 2009; 7(2): 181-200.

34.National Collaborating Centre for Aboriginal Health (NCCAH). Housing as a Social Determinant of First Nations, Inuit and Metis Health. 2010. Available at URL: www.nccah-ccnsa.ca/docs/fact%20sheets/social%20determinates/NCCAH_fs_housing_EN.pdf. Accessed 11 Dec 2013.

35.Nazroo, JY, Williams DR. The social determination of ethnic/racial inequalities in health. In: Marmot, M., Wilkinson, R.G. (eds). Social determinants of health. 2nd ed. Oxford: Oxford University Press, 2006; 238-66.

36.Ward A. The social epidemiologic concept of fundamental cause. Theoretical Medicine and Bioethics 2007; 28(6): 465-85.

37.Moosa-Mitha M. Situating anti-oppressive theories within critical and difference-centered perspectives. In: Brown L, Strega S (eds). Research as resistance: critical, Indigenous and anti-oppressive approaches. Toronto: Canadian Scholars press, 2005.

38.Reimer K. Anderson JM. Postcolonial nursing scholarship: from epistemology to method. Advances in Nursing Science 2002; 25(1): 1-17.

39.Brooks C. "I Just Didn't Tell Anybody What I Was Doing": Aboriginal Women Cancer Survivors Visualize Social Support. Canadian Woman Studies/les cahiers de la femme 2011; 28 (2/3): 63-70.

40.Anderson JM. Gender, race, poverty, health and discourses of health reform in the context of globalization: A postcolonial feminist perspective in policy research. Nursing Inquiry 2000; 7: 220–9.

41.Anderson JM. The conundrums of binary categories: Critical inquiry through the lens of postcolonial feminist humanism. Canadian Journal of Nursing Research 2004; 36(4):11-6.

42.Browne AJ, Smye VL, Varcoe C. Postcolonial-feminist theoretical perspectives and women's health. In: Morrow M, Hankivsky O, Varcoe C (eds). Women's health in Canada: Critical perspectives on theory and policy. Toronto: University of Toronto Press, 2007; 124-41.

43.Dion Stout M, Klipling GD, Stout R. Aboriginal women's health research: Synthesis project final report. Ottawa, ON, Canada: Centres of Excellence for Women's Health, 2001.

44.Anderson JM, Perry J, Blue C, Browne AJ, Henderson A, Lynam J, Reimer Kirkham S, Seminiuk P, Smye V. 'Re-writing' cultural safety within the postcolonial/postnationalist feminist project: Toward new epistemologies of healing. Advances in Nursing Science 2003; 26(3):196-214.

45.Browne A, Fiske J. First Nations women's encounters with mainstream health care services. Western Journal of Nursing Research 2001; 23(2): 126-147.

46.Royal Commission on Aboriginal Peoples. People to people, nation to nation: Highlights from the report of the Royal Commission on Aboriginal Peoples. Ottawa: Minister of Supply and Services Canada, 1997.

47.Wood P, Schwass M. Cultural safety: a framework for changing attitudes. Nursing Praxis N Z 1993; 8(3): 4-15.

48.Browne AJ, Fiske J, Thomas G. First Nations women's encounters with mainstream health care services and systems. Vancouver, B.C.: BC Centre of Excellence for Women's Health, 2000.

49.Rigney L. Internationalization of an Indigenous anti-colonial cultural critique of research methodologies: A guide to Indigenist research methodology and its principles 1999. Journal of Native American Studies Review; 14(2):109-21.

50.Duffy L. 'Step-by-step we are stronger': Women's empowerment through photovoice. Journal of Community Health Nursing 2011; 28(2):105-16.

51.Harrison B. Seeing health and illness worlds: Using visual methodologies in a sociology of health and illness: A methodological review. Sociology of Health and Illness 2002; 24(6): 856-72.

52.Liamputtong P. Researching the vulnerable: A guide to sensitive research methods. London: Sage Publications, 2007.

53.Wang C. Photovoice: A participatory action research strategy applied to women's health 1999. Journal of Women's Health;8:185-92.

54.Glaser B, Strauss A. The discovery of grounded theory: Strategies for qualitative research. New York, NY: Aldine de Gruyter, 1967.

55.Bryant A, Charmaz K. The SAGE handbook of grounded theory. Thousand Oaks, CA: Sage Publications, 2007.

56.Moffitt P, Robinson Vollman A. Photovoice: Picturing the health of Aboriginal women in a remote northern community 2004. Canadian Journal of Nursing Research; 36(4):189-201.

57.Harley A. Picturing Reality: Power, Ethics, and Politics in Using Photovoice. International Journal of Qualitative Methods. 2012;11(4):320-39.

58.Minkler, M., & Wallerstein, N. (eds.). Community based participatory research for health. San Francisco: Jossey-Bass, 2003.

59.Crist JV, Grunfeld EA. Factors reported to influence fear of recurrence in cancer patients: a systematic review. Psycho-Oncology 2012; 22(5):978-86.

60.Simard S, Savard J, Ivers H. Fear of cancer recurrence: Specific profiles and nature of intrusive thoughts. Journal of Cancer Survivorship 2010;4:361-71.

61.Vickberg SM. The concerns about recurrence scale (CARS): A systematic measure of women's fears about the possibility of breast cancer recurrence. Annals of Behavioral Medicine 2003;25:16-24.

62.Thewes B, Brebach R, Dzidowska M, Rhodes P, Sharpe L, Butow P. Current approaches to managing fear of cancer recurrence; a descriptive survey of psychosocial and clinical health professionals. Psycho-Oncology 2013;Nov 1:1-7.

63.Fobair P. Oncology social work for survivorship. In: Ganz P (ed). Cancer survivorship: Today and Tomorrow. New York: Springer, 2007.

64.Aufdenkamp M. Fear of recurrence: What you should know. Nebraska Nurse 1997; 30 (2): 32.

65.Simard S, Sevard J. Fear of cancer recurrence inventory: Development and initial validation of a multidimensional measure of fear of cancer recurrence. Supportive Care in Cancer 2009;17:241-51.

66.Humphris GM, Rogers S, McNally D, Lee-Jones C, Brown J, Vaughan D. Fear of recurrence and possible cases of anxiety and depression in orofacial cancer patients. International Journal Oral Maxillofac Surgery 2003;32:486-91.

67.Leake RL, Gurrin LC, Hammond IG. Quality of life in patients attending a low-risk gynaecological oncology follow-up clinic. Psychoncology 2001;10:428-35.

68.Lee-Jones C, Humphris, G, Dixon R, Hatcher MB. Fear of cancer recurrence: A literature review and proposed cognitive formulation to explain exacerbation of recurrence fears. Psych-Oncology 1997;6:95-105.

69.Jadoon NA, Munir W, Shahzad MA, Choudhry ZS. Assessment of depression and anxiety in adult cancer outpatients: a cross-sectional study. BMC Cancer 2010; 10:594-600.

70.Wong CA, Bramwell L. Uncertainty and anxiety after mastectomy for breast cancer. Cancer Nursing 1992;15:363-71.

71.Stanton AL, Danoff-Burg S, Huggins ME. The first year after breast cancer diagnosis: Hope and coping strategies as predictors of adjustment. Psycho-Oncology 2002;11:93-102.

72.Polinsky ML. Functional status of long-term breast cancer survivors: Demonstrating chronicity. Health Social Work 1994; 19:165-73.

73.Meyer L, Aspegren K. Long-term psychological sequelae of mastectomy and breast conserving treatment for breast cancer. Acta Oncologica 1989;28:13-18.

74.Lasry JC, Margolese RG. Fear of recurrence, breast-conserving surgery, and the trade-off hypothesis. Cancer 1992; 69: 2111-5.

75.King MT, Kenny P, Shiell A, Hall J, Boyages J. Quality of life three months and one year after first treatment for early stage breast cancer: Influence of treatment and patient characteristics. Quality of Life Research 2000; 9:789-800.

76.Van den Beuken-van Everdingen MHJ, Peters ML, de Rijke JM, Schouten HC, van Kleef M, Patign J. Concerns of former breast cancer patients about disease recurrence: a validation and prevalence study. Psycho-Oncology 2008; 17:1137-45.

77.Constanzo ES, Lutgendorf SK, Mattes ML, Trehan S, Robinson CB, Tewfik F, et al. Adjusting to life after treatment: distress and quality of life following treatment for breast cancer. British Journal of Cancer 2007; 97:1625-31.

78.Janz N, Hawley S, Mujahid MS, Griggs JJ, Alderman A, Hamilton AS, et al. Correlates of worry about recurrence in a multiethnic population based sample of women with breast cancer. American Cancer Society 2011; 117:1827-36.

79.McGinty HL, Goldenberg JL, Jacobsen PB. Relationship of threat appraisal with coping appraisal to fear of cancer recurrence in breast cancer survivors. Psycho-Oncology 2012; 21:203–10.

80.Thomas-MacLean R, Miedema B. Feminist Understandings of Embodiment and Disability: A "Material-Discursive" Approach to Breast Cancer Related Lymphedema. Atlantis: A Women's Studies Journal 2005; 30(1):92-103.

81.Gould J. Lower-income women with breast cancer: Interacting with cancer treatment and income security systems. Canadian woman studies/les cahiers de la femme. Special Issue: Women's Health and Well-Being 2004; 24(1):31-6.

82.Schnarch B. Ownership, control, access and possession (OCAP) or self-determination applied to research: A critical analysis of contemporary First Nations research and some options for First Nation communities. Journal of Aboriginal Health 2004;1:80-95.

83.Wilkinson S. Women with breast cancer talking causes: Comparing content, biographical and discursive analyses. Feminism & Psychology 2000;10:431-60.

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