

# “I Just Didn’t Tell Anybody What I Was Doing”

## Aboriginal Women Cancer Survivors Visualize Social Support

CAROLYN BROOKS

*On connaît très peu les expériences des femmes autochtones qui ont vécu le cancer du sein et le soutien social qui les accompagne. Cet article fait le portrait et raconte l’histoire de douze femmes autochtones survivantes du cancer du sein. Leur histoire révèle des identités à multiples facettes, des situations communes et des influences historiques et sociales comme le racisme qui a troublé leur expérience de l’aide apportée et de leur survie.*

I open this article with a conversation I had with a female Elder who shared the story of her 97-year-old *kokum*.<sup>1</sup> Her *kokum* did not speak English and did not understand what was happening to her, many years ago, when the doctors cut off her breasts—first one, and then three years later the other. It was not until her *kokum* asked an Aboriginal cleaning woman at the hospital to speak to the doctor that she learned she had breast cancer and was told that “it was a good thing she was old and didn’t need her breast anymore” (Campbell 5). In support of recruitment for our research project, entitled: *Visualizing Breast Cancer: Exploring Aboriginal Women’s Experiences* (VBC<sup>2</sup>), this same female Elder wrote about the importance of learning from other Aboriginal women’s narratives (Campbell 5). Since that initial conversation, we have been privileged to have 12

Aboriginal<sup>3</sup> breast cancer survivors who live in Saskatchewan participate in this VBC study, and share their stories.<sup>4</sup>

In the spirit of participatory and photovoice<sup>5</sup> research, the VBC participants, who were all Aboriginal women breast cancer survivors from Saskatchewan, participated in focus groups, in-depth individual interviews, and took pictures which represent their breast cancer experience. Photovoice is a research tool that empowers research participants to tell their stories and to assess their own needs visually (Harrison) using photography. It is their “lives through their eyes” and their accounts and visual images of support that fill these pages.

Although Canadian cancer registries collect little statistical data across different racial groups (Wilkinson) incidence of breast cancer for Aboriginal women is said to be rising more quickly than for non-Aboriginal women (Canadian Cancer Society), and survival rates are poorer (Marrett, Jones and Wishart, 2004). Cancer care, support, and survivorship experiences are said to be “heavily influenced” by social norms and values influenced by race, gender and class (Wilkinson) yet experiential research here is infrequent (Leedham and Ganz; Lopez, Eng, Randall-David and Robinson). Although there are many studies that reveal the social support needs of breast cancer sur-

vivors (Wilkinson; Mansyur, Amick, Harrist and Franzini), there is less research on Aboriginal women’s specific support needs (Garroute, Kunovich, Jacobsen and Goldberg). It is not known what resources are available to Aboriginal breast cancer survivors, nor has the meaning of breast cancer been explored from the perspective of Aboriginal women. The few studies which have been done reveal cultural silences around speaking about cancer: “Speaking about cancer brings negativity”: ... “I am not sure, if, its not the breast I don’t think it’s the breast thing, I think it’s a culture thing, we don’t want to hear it” (Mitchell et al. 3).

This article is a reaction to the prevalence of breast cancer and the calls for more research into the effect of race, gender, and class on cancer care and cancer experience (Leedham and Ganz). Specifically, I explore Aboriginal women’s experiences of breast cancer and social support. The theoretical framework which best applies is postcolonial feminism,<sup>6</sup> allowing an understanding of the influence and intersectionality of social forces (including gender, class, culture, race, and colonial histories), while recognizing and accounting for heterogeneity of women’s experiences. The postcolonial-feminist perspective and their use of ‘cultural safety’ help unravel the complex support needs of the VBC participants.<sup>7</sup>

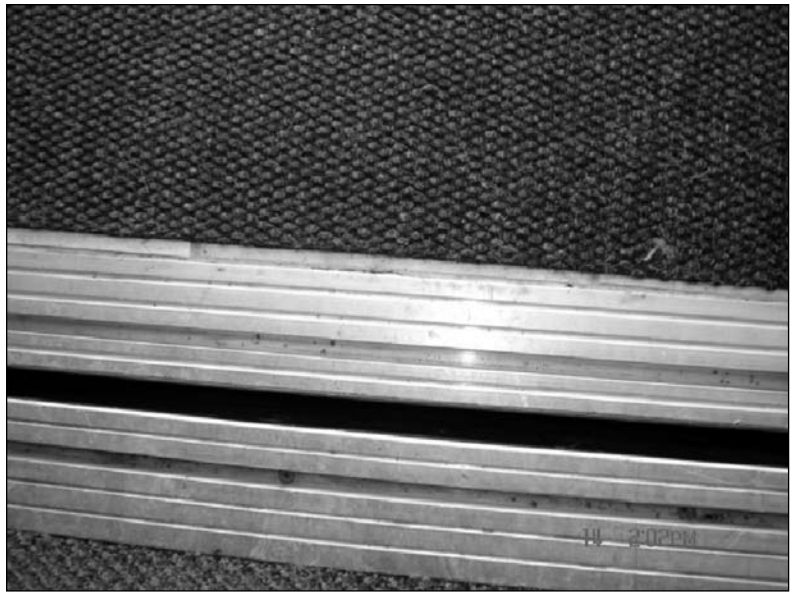
## Postcolonial Feminism and Cultural Safety

Postcolonial feminism combines feminist, anti-racist and postcolonial discourse and questions the link between colonialism, neo-colonialism, and the impact of race(ism) on women's lives (Anderson). In order to link these abstract theoretical lenses to the everyday experience of the research participants, I apply the postcolonial concept of cultural safety. Cultural safety was introduced by Indigenous nurses in the postcolonial context of New Zealand (Browne, Fiske and Thomas). Cultural safety was reworked by postcolonial feminist and other critical authors in Canada (see, for example, Anderson et al; Browne, Fiske and Thomas) as a lens to explore inequalities and institutional and individual discrimination resulting from colonization.

In the Canadian context, a number of authors have used cultural safety to explore relationships between First Nations people and health care workers (Browne and Fiske). This research has analyzed culturally safe and unsafe practices from the perspectives of First Nations peoples and health care workers (Browne). To the best of my knowledge the concept of cultural safety has been limited to understanding relationships between health care and First Nations and other racialized peoples and normally found in critical nursing and healthcare policy literature. I extend the use of cultural safety to analyze the women's stories and pictures in the VBC research in relation to social support. Because cultural safety simultaneously views individuals in their locations, related to colonial marginalization, I argue that it offers a unique lens to understand themes of social support and to identify culturally unsafe and safe practices.

### **Conceptualizing Cultural Safety**

Authors of cultural safety define it by talking about culturally unsafe and safe practice. Culturally unsafe



"Falling Through the Cracks." Photo: Sandra.

practice is defined as: any actions which diminish, demean, or disempower the cultural identity and well being of an individual (Whanau Kawa Whakaruruhau)—the three Ds (Wood and Schwass, 1993). Culturally safe practices "recognize, respect and acknowledge the rights of others" (Cooney 6)—the three Rs (Wood and Schwass). Applying the lens of postcolonial feminism to cultural safety draws attention to social positioning within historical and social changes.

### **Applying Cultural Safety**

The postcolonial-feminist perspective and cultural safety helps unravel the complex ways the women have experienced support networks regarding breast cancer. Cultural safety therefore may reveal "taken for granted processes and practices that continue to marginalize Aboriginal voices and needs" (Anderson et al. 199).

Based on the findings and using categories elicited from the cultural safety literature, two broad themes regarding social support and culturally unsafe practices emerged. These are: 1. not being visible and hiding identities (feelings of being dismissed); 2. lives without context (feelings of being demeaned and disempowered).

### **Culturally Unsafe Practices**

#### ***Not Being Visible and Hiding Identities***

The VBC participants described concern with not being visible in health documents and mainstream media. They talked about breast cancer being represented in the media as an *older white woman's disease*. Tina, for example, said:

*I feel like we are the forgotten race—when you watch the news, they talk about everyone else and Natives are not mentioned.*

The women's concern with not being seen related to their images, lives and needs and this invisibility was linked to racism. Sandra talks about feeling as though Aboriginal women's needs are not addressed, not even seen. The lack of culturally relevant support programs and sensitivity were symbolic of Aboriginal women *falling through the cracks* shown in Sandra's symbolic image of an elevator shaft:

*We've fallen into the cracks. And nobody can really see ... And nobody really cares because they step over us all the time... People walk over, get in and out of this eleva-*



"Sweetgrass." Photo: Mary.



"Drum." Photo: Shelly.

*tor everyday. But very few people will look in the cracks to see what's down there, or look in there.*

Sandra's<sup>8</sup> picture of the elevator shaft visually demonstrated this *invisibility*, by suggesting that *very few people look through the cracks*.

Similarly, the VBC participants who chose to practice traditional medicine, ceremonies and have strong First Nations spiritual beliefs, talked about

hiding this from mainstream health care workers—practitioners and support groups and social workers. These practices were often very important to the women, as shown through their numerous photographs<sup>9</sup> and stories. For example, Mary explained how sweetgrass and smudging helped her keep focused and balanced.

Shelley explains the significance of the drum in Aboriginal culture and for her healing:

*And I mean the drum, I mean drum is quite significant in Aboriginal culture ... it represents the heart beat of ... Mother Earth and ... the connection from me to, you know, the, the spirit world.... I use it for praying. I use it for meditating. I use it in the sweat lodge. I use it to sing. I use it ... during some healing ceremonies....*

The participants felt their beliefs and practices were dismissed, not responded to well and felt they risked being told not to practice them.

*I didn't even tell them I went to sweat lodges or anything, for fear that they would tell me not to go.... So I just didn't tell anybody anything what I was doing, I just went ahead and did it myself. (Mary)*

Participants who healed themselves through alternative practices, such as Mary, Margaret, Marie and Dorothy and who did not follow specific medical orders, felt that they were at risk for being labelled irresponsible. Margaret said that she was *told not to say anything*. The women assumed that their behaviours, which they defined as outside of the mainstream mentality, would be judged. As a result, these women hid an important part of themselves.

Although the women provided a critique of not being visible, being seen was also related to culturally unsafe practices. The women talked about being wrongly identified and having their lives misunderstood. My next example shows participants description of feeling falsely identified and Othered in cancer support groups. Relevant here are the women's expressions of not feeling visible and ways they hid their identities within these cancer support groups.

The VBC participants expressed feeling that they had no support. Four of the women talked about feeling invisible or out of place within existing support groups. These women



"Bouquet." Photo: Sandra.



"Evening of the Full Moon Ceremony." Photo: Shelley

also said they felt marginalized, like outsiders or intruders, who lacked a connection to others within the group. Powerful imagery was used, for example, by Sandra to represent feelings of misrepresentation in support groups surrounded by mainly older Caucasian women. She uses a bouquet of flowers, roses with a carnation in the middle to describe her feelings within the support groups. In this analogy Sandra identifies with the carnation, commenting how it is not seen for its long life and beauty, but

often overlooked for the short lived "perceived perfection" of the roses. She conveys:

*It was just more flowers ... the carnation in the middle of all those roses ... is kind of what I felt like sometimes... When I'm sitting in a group of all of these Caucasian women ... I just felt, you know they're all so perfect and everything, and they're so beautiful and they're so lucky to be privileged.*

She also talks about how carnations last longer than roses and are beautiful yet not as fragile as the rose.

*But yet, carnations are very long living, very you know. They last so much longer... they're not so fragile... They're not so fragile, but still very beautiful.*

Sandra suggests the rose and the carnation are misunderstood and that race is similarly misunderstood.

Barriers to support groups were mostly concerned with an assumed similarity between survivors. The women talked about the problems inherent in not acknowledging differences in class, race, culture and experience. Three participants gave examples of what wasn't seen:

*I have children, and I can't lower my stress because I have no job, I have no income, I have kids to feed... the one focus group... they [the other women] were talking about ... taking time off work and taking their family to Hawaii when they were diagnosed.... I can only dream of that...*

When social problems related to class or race were addressed, the women talked about how this was often misrepresented by de-contextualizing a social problem and viewing this as an individual problem. Sandra, for example, recalls an incident where she needed to buy the fitted bra, but couldn't afford it. She explains that another woman in her support group offered to buy Sandra the bra:

*Like I need a 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?*

Sandra's response was that this woman and the entire group of women did not really understand the larger problem.

### *Lives Without Context*

The final theme related to culturally unsafe practices, reflects the women's concerns they that are falsely identified from a failure to recognize underlying social and historical factors. The women talked openly about colonial histories and how this has affected theirs and others lives, and the different and complex ways that people have coped and responded.

spoke about women being unwilling to do self-examinations or to even talk about cancer. As Marjorie says:

*With us there has been so much intergenerational damage.... Everything is very hush hush.... We need to tell [each other] it is okay to take your shirt off and bra off—so what if you are lopsided, you are alive.... But we have been hushed....*

situation and being silenced overtime. She also said that she was given the strength to speak out because of her family. She therefore talked about feeling that 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 lack of trust and shy disposition:

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**“With us there has been so much intergenerational damage.... Everything is very hush hush.... We need to tell [each other] it is okay to take your shirt off and bra off—so what if you are lopsided, you are alive.... But we have been hushed.”**

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Yet the women also felt that this was not widely understood.

For example, four of the VBC participants talked about the misinterpretation of Aboriginal women's shyness or passivity. The participants were concerned that shyness often leads Aboriginal women not to ask questions about health concerns and often to not even talk about cancer, and may be part of the reason why their support needs and concerns have been left unaddressed for so long. Three of the VBC participants said that this shyness and passivity is falsely interpreted as being a cultural norm and part of Aboriginal women's identity. These women said that these are false and harmful generalizations. Aboriginal women and Aboriginal people are not simply silent but have been silenced.

The majority of the participants recounted at some point in their interviews that it is common that First Nations peoples may choose *not to speak out* (Marion). They explained that many Aboriginal peoples have become silenced overtime, especially through their experience of marginalization, residential schools, residential day school and histories of violence against themselves and their cultures.

Marjorie and Marion capture an intergenerational analysis when they

Marion spoke of her own experience and how silence was learned in her childhood at residential day schools. Day schools were government funded, church-run residential schools, but the children lived in boarding houses, orphanages, hostels and convents rather than the dormitories used in residential schools:

*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.*

Sandra expresses how silence is a reaction to racism, and being responded to in certain ways. This builds overtime:

*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 don't ask questions.... I didn't want them to think I was stupid.*

Sandra talked about her own life

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

Sandra and Marion's identities were both silenced, but finding their voices points to another important theme—that individuals respond to social forces in their lives differently. Although this seems obvious, it is often not acknowledged within social theory. Critical social theory, for example, often identifies the effects of social forces on peoples' lives, without recognizing social agency. This emphasizes the importance of intersecting and complex social and economic relations, and social agency. The emphasis on the women's agency does not minimize the impact of colonial histories and oppression—nor “the importance of critical race and gender analysis” (Anderson et al. 201), but points to the importance for the concepts we employ to handle complex social forces and multiple agencies.

### **Discussion**

The women's stories and pictures define culturally unsafe practices as:



"View from Marie's Home." Photo: Marie

ways in which they were not seen (denied) and lives decontextualized (disempowered). The research findings and women's stories provide insight into the importance of locating the women's lives and ways of knowing in larger historical, social, economic and political forces, defined in postcolonial-feminist literature as cultural safety. From the postcolonial-feminist standpoint, research must move beyond identifying who the women are and what they do, to how they are perceived and treated and how this impacts their support systems and health.

The decontextualization and misrepresentation of identity, I attest, affects policies in health care and the larger society. Attending to a cultural safety lens may encourage health practitioners, support workers and support groups, to look beyond descriptive cultural difference or cultural sensitivity to gain deeper understanding of social forces and factors which influence Aboriginal women's lives—including the refutation of traditional spirituality and medicines. What the themes here suggest is that we need to gain a deeper respect and contextualized understanding of women's silence, resilience, fears and isolations; realities of socio-eco-

nomics; and traditional medicine and spirituality. The resulting model acknowledges limits of cross cultural awareness, and the importance of education and safeguarding against negative stereotypes and Othering Aboriginal women.

Information about breast cancer is criticized as assuming that all women are the same (see, for example, Friedman and Hoffman-Goetz). Some postcolonial feminist authors argue that privileging the voice and visual perspectives of marginalized peoples helps work towards social equity, challenge neo-colonial visions/stereotypes and provides more respectful empowering images, which may influence more equitable policy (Haraway cited in Poudrier and Thomas-MacLean). Visual images may have transformative potential (Pink), "whereby neo-colonial discourse in health care holds a problematic image of Aboriginal women ... photovoice can reverse the colonial gaze by asking women to reveal the world as seen through their eyes" (Poudrier and Thomas-MacLean). The women are excited about the potential of their own pictures to provide visibility of Aboriginal women survivors towards culturally safe awareness and increased support:

*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)

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<sup>1</sup>Kokum is the Cree term for Grandmother.

<sup>2</sup>The original VBC research was funded by: The Canadian Breast Cancer Research Alliance (CBCRA); Social Sciences and Humanities Research Council of Canada Doctoral Fellowship; Indigenous Peoples Health Research Center (IPHRC) and the Saskatoon Health Research Foundation. This research was completed by myself (research manager) and two other researchers; Roanne Thomas-MacLean and Jennifer Poudrier (Co-PIs) from September 2005 to 2008. Drs MacLean and Poudrier were the PIs with CBCRA research funding and I was responsible for the data collection.

<sup>3</sup>I use the term 'Aboriginal' to be inclusive to all of the women, referring collectively to Métis, Inuit and First Nations.

<sup>4</sup>As a non-Aboriginal researcher I was concerned that this research may be an intrusion into women's very personal lives. An unexpected privilege were the relationships I formed with the women and their willingness to share their lives, stories, pictures and trust with me. A few of the women said that it was less important that I was an Aboriginal woman, and more important that I would listen com-

pletely to their stories. I express my deepest appreciation to the women whose stories and pictures are shared here and hearten this work. I feel privileged to have met each woman and hope others learn from their stories as I have.

<sup>5</sup>To the best of our knowledge photography has not been used in connections with Aboriginal women's experiences with breast cancer, nor have visual methods been used within the social sciences to explore the meaning of breast cancer more generally.

<sup>6</sup>Despite a consensus that themes in postcolonial writing are in opposition to colonialism, there are ongoing debates regarding its meaning and whether theories associated with postcoloniality apply within Canadian contexts and to First Nations literatures (Moss).

<sup>7</sup>Three other articles have developed different themes using this VBC data. Other themes developed include: the importance of age (Thomas-MacLean, Poudrier and Brooks); photovoice methodology with Aboriginal women (Brooks, Poudrier and Thomas-MacLean) and health care (Poudrier and Thomas-MacLean).

<sup>8</sup>The majority of the participants for this study did not wish their pictures or their transcripts to remain anonymous; they preferred to be credited openly for their contributions, especially because they felt this would be more effective in helping other women survivors and other Aboriginal women experiencing cancer. They wanted to be identified, using their real names and the pictures of themselves and their families, who also provided written consent. We recognized the participants' rights to be identified if they wished and amended our ethics. This speaks volumes of the participants' engagement with this methodology as well as their willingness to share their lives to assist others.

<sup>9</sup>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.

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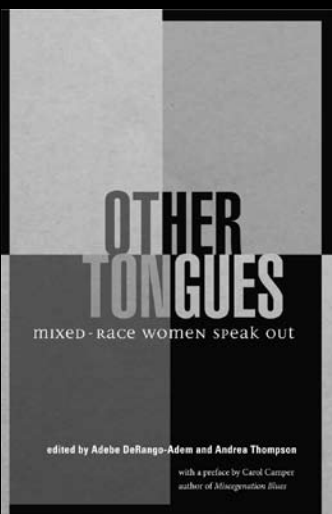
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## MALCA LITOVITZ

### What I'd Like to Hear

Tell me healing stories under the tree.  
Let me sit at your feet and know  
that all shall be well.

Look into my eyes as you speak  
and see vastness mirrored there -  
sky and earth.

Let me heal at your feet  
receiving gifts and blessings.

Fill my bag with wisdom  
and practices to still me.

Let me see enchantment  
in the trembling leaves  
and hope in the October sky.

*Marlca Litovitz's poetry appears earlier in this volume.*

## ILONA MARTONFI

### The Black Box

Gazette Extra: *Death from the sky: War on America!*  
Eerie silence in downtown Montreal:

Hijackers crash a plane into the World Trade towers  
— one hundred floors crumble. I watch it on television.

People are on alert. They huddle in small, silent groups.  
I am thinking about my youngest daughter in

San Francisco, thousands of miles away.  
Eldest sister Erna in Los Angeles —

"I don't have space for this," I tell my son.  
"I am dealing with something bigger. My mother."

"I will have the mastectomy September 17," she said.  
"I am not feeling well. I am tired."

*Ilona Martonfi's poetry appears earlier in this volume.*