

**Aboriginal Women's Visions of Breast Cancer Survivorship:
Intersections of Race(ism)/Class/Gender and
"...Diversity as *We Define It*"¹**

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by

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¹ Monture-Angus, 1995: 178

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² Monture-Angus, 1995: 178

ABSTRACT

This dissertation combines the empowering methodology of photovoice with focus groups and in-depth interviews, to develop a contextual understanding of the meaning of breast cancer for Aboriginal women. Photovoice is a participatory action research method, as well as a process towards health promotion. The participants in this study took pictures to document their realities and engaged in critical reflection individually and in a group process, using images and stories to advocate community and policy changes. A combination of epidemiological, sociological, and anti-oppressive theoretical lenses were used to analyze the women's stories and data, which served to acknowledge heterogeneity, while integrating multiple social contexts.

The emerging framework revealed multi-faceted identities, commonalities of situation, and prominent social forces that affect identity and cancer experience. Interpretation of the women's stories and pictures resulted in four general themes: 1) adjusting to physical and psychological changes; 2) the need for culturally relevant sources of support; 3) shifting identities; and 4) personal and political advocacy/policy directions. Prominent social forces include: culturally derived meanings of identity and sexuality, cultural and historical experiences/traditions of Aboriginal peoples, racism and racial stigmas, and socio-economic inequalities. Breast cancer experiences are shown to be significantly linked to history and the impact of colonization and neo-colonialism. Findings also point to the importance of recognizing heterogeneity, which does not minimize the impact of colonial histories and oppression, but points to the importance of employing an anti-oppressive theoretical lens and research framework, able to handle complex intersecting social forces and multiple agencies. These findings provide support for using the photovoice methodology with Aboriginal women, especially for its ability to shift power from researchers to insiders, privilege Indigenous knowledges, and for providing opportunities for critical and multiple tellings. The dissertation concludes by introducing a governmentality lens, which questions whether photovoice methods can address the social and historical problems at the level of policy. This study directs our attention to the need for further research on: 1) the link between breast cancer experiences to historical, political, and social contexts of lives of Aboriginal peoples; and 2) the potential of photovoice methods to affect policy and social justice.

DEDICATION

I want to express my deepest appreciation to the women whose stories and pictures are shared here and hearten this work. I make this dedication to: Cheryl, Dorothy, Margaret, Marie, Marjorie, Marion, Mary, Sandra, Shelley, Tina and the other women who shared their stories with me, but chose to remain anonymous. I feel privileged to have met you and hope others learn from you as I have.

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Chapter 1 Opening of the Research

I do not believe that justice can even exist without women's central participation in all aspects of that system. Women are the doorway through which all life passes (Monture-Angus, 1995: 263).

1.1 Introduction

This dissertation was opened by a conversation I had with a female Elder who shared the story of her 97 year old kokum. Her kokum did not speak English and did not understand what was happening to her 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, 2005: 5). In the spirit of this research and inviting others to share their stories with me, she writes about her own story:

...my 97 year old kokum who passed away several years ago...had come to spend a month with me... I was finishing the breakfast dishes while she took her bath when she called me in to help her. I stopped mid-way into the bathroom. The facecloth she was holding in front of her had slipped away. She was breast less, covered with thick ugly scar tissue and around the place where her breasts had been were what looked like huge black stitches. 'Oh my god kokum, what happened?' I was horrified. She grabbed the cloth and held it in front of her. 'The doctor cut them off a long time ago,' she said. 'I went to the hospital and after a few days they took me to this room and gave me a needle, when I woke up the first one was gone.' Three years later she got sick again and went back to the same hospital and the other breast was removed (Campbell, 2005: 5).

She emphasized the importance of learning from other Aboriginal women's narratives, especially because of the little Indigenously driven information on breast cancer and its high rate of prevalence.

Since that initial conversation, I have been privileged to have twelve Aboriginal breast cancer survivors who live in Saskatchewan, share their stories with me. Their accounts fill these pages. The women's stories call attention to a number of issues that arise for breast cancer survivors and identities connected to being Aboriginal women, rural women, anti-racists, environmental activists, community leaders, breast cancer activists, community activists, poor women, employed women, teachers, counsellors, labourers, trappers, artists, farmers, film-makers, Pipe-carriers, Elders, healers, wives, partners, mothers, step-mothers, foster-care mothers, grand-mothers, kokums, daughters, granddaughters, aunts, cousins, sisters, friends and compassionate citizens.

1.2 An Introduction to the Women

As an introduction to each of the women, I bring forward one picture and a few details they used to describe their cancer diagnoses and specific identities as well as one or two acquainting characteristics which arose from their pictures and stories. The pictures represent one of their preferred photographs. Six of the women are First Nations women who are living in one of the major cities in Saskatchewan. Four women are living on reserve and in more remote areas of Saskatchewan and another two women are from rural areas. All of the participants were young when they were first diagnosed with breast cancer—five of the women were diagnosed before they were 40 years old. All of the women were consulted to have their pictures and identities used.

1.2.1 Marjorie



Marjorie with one of her grandchildren

Marjorie is a First Nations woman of Saulteaux ancestry with one child and three grandchildren. Marjorie was diagnosed with breast cancer on April, 1992 when she was only 31 years old. She was diagnosed and treated again at 43, in June, 2004. Marjorie is presently coping with a new recurrence in 2008 at 47. When I first met Marjorie, I was struck by her strong, witty and perceptive personality. She is not afraid to say exactly what is on her mind, standing strong against perceptions of racism. Marjorie has endured abuses through residential school, yet talks about finding strength and resilience through hard times. Recently she was evicted from her apartment and was homeless and living in an emergency shelter. After her eviction, she was interviewed for a news story entitled “No Place to live; no place to die: homeless cancer victim seeks place to pass away comfortably” (Warick, December 12th, 2008: A1). As a result of this attention she received thousands of dollars in donations. She has an acrimonious, humorous and sarcastic way, which makes people stand up and listen.

1.2.2 Sandra



Sandra with one of her grandchildren

Sandra is a member of the Ahtahkakoop first Nation in Saskatchewan and, like Marjorie, was diagnosed with breast cancer very young. Sandra was diagnosed in October, 1999 at only 36 years old and underwent surgery and chemotherapy. She spoke about losing her mother to breast cancer and her fear for her daughters and granddaughters with the extensive occurrence of cancer in her extended family. Sandra holds a Bachelor of Arts degree in Indian Studies and an Indian Communication Arts Certificate from the First Nations University of Canada and is employed as a full time researcher. Sandra is the Vice-President of Breast Cancer Action Saskatchewan in Regina and her passion seems to be as a breast cancer activist for Aboriginal women. Sandra aims to be a voice for other Aboriginal woman who can't speak for themselves because of years of racism, violence and experience in residential schools. During this study Sandra created a documentary film on her families experience with cancer called: *One of the one percent—The Sandy Ahenakew Story*. She uses her humour and her engaging personality to teach about the specific needs, strengths and sufferings of Aboriginal women, including their shared discrimination and suffering from colonial histories.

1.2.3 Marion



Marion and her children

Marion is a First Nations woman of Saulteaux ancestor who was diagnosed at 39 in 2001. She also went through surgery and chemotherapy. Marion is married with three children, one foster care child, and one grandchild. She talks about her family and her extended family as being very important in her healing, including sisters and her sister-in-laws who cut their long hair and braids to help her face chemotherapy. Marion shared stories of women on her reserve who used denial and alcohol to cope when they were diagnosed with breast cancer. Her personal story represents movement from being quiet, shy and dependent on others, to finding her voice and strength. She realized that facing cancer was something that she couldn't rely on others for, and she said this led to strength in all areas of her life. Like Sandra, Marion speaks of wanting to support other Aboriginal women going through breast cancer and wished she had met another Aboriginal survivor while she was going through her treatment. Whereas Sandra wants to be a voice for Aboriginal women, Marion's goal is to support others through developing support and support groups.

1.2.4 Dorothy



Dorothy

Dorothy is a First Nations woman of Cree Ancestry, diagnosed with breast cancer in 2002 when she was 48 years old. She is married by common law and has one child, two grandchildren and one foster care child. Although Dorothy has a soft spoken exterior, she is a powerful community activist, environmentalist and community leader. Similar to Marion and Sandra, Dorothy's desire is to help other Aboriginal women and Aboriginal peoples with cancer, but her efforts are more directed to fundraising and addressing environmental and social conditions on reserves. Dorothy's pictures visualized problems with housing, water, and the environment. Because of the poor conditions on her own reserve Dorothy moved into the city and lived in a trailer with her daughter and grandchildren during treatments. Traditional and Aboriginal healing, teachings, and medicine, are also an important part of Dorothy's story. For example, her fear of chemotherapy and surgery were deepened because she had always been taught that if you lose a body part or cut your hair someone in your family or community will die. Her husband, a traditional healer, smudged her braid and said she would heal, but she would look like *Crazy Horse*.

1.2.5 Marie



View from Marie's Home

Marie is a First Nations woman of Cree ancestry who was first diagnosed with breast cancer in 1986 at 45 years old and again in 1999 at 58. She underwent radiation in 1986 and a mastectomy in 1999. Like Dorothy, Marie is from a more remote area in Saskatchewan and has strong spirituality which includes practice in traditional ceremonies: Powwows, Sundance and Pilgrimages. She is married, has a grade six education, and describes herself as a pensioner. Also similar to Dorothy, Marie is both soft spoken and yet a very strong and productive woman often engaged in physically challenging labour, like trapping. Marie spoke openly about her own problems with alcohol and prescription medication and how this affected her illness. Also similar to Dorothy, Marie wants to help educate other Aboriginal women and to bring relevant breast cancer information to reserve communities. Marie asked us to photograph her scar as a way to help other women to face the illness and not be ashamed of their own surgeries and physical changes. I met Marie a second time at a retreat in Saskatoon for residential school survivors. I feel that she has a calming and spiritual way of teaching about the impact of colonial histories.

1.2.6 Shelley



Evening of the full moon ceremony

Shelley is a two-spirited Métis woman who was diagnosed with breast cancer in 1998 when she was 44 years old. Shelley underwent surgery for her cancer. She was the only participant who didn't experience fear upon her initial diagnosis and was able to continue with her regular life routine. Shelley is an Aboriginal Counsellor and a Pipe Carrier and similar to Dorothy and Marie spoke about the importance of Aboriginal spirituality in her life and healing. Shelley's pictures of rocks, ceremonies, colours, moons and trees showed the important link between Aboriginal spirituality and nature. Shelley's partner has three daughters and four grandchildren. Reflecting on her life through her pictures, she shared how important strong role models and relationships are in wellness and healing. She talked about resilient grandmothers and her mother who thrived spiritually, mentally and emotionally in the face of difficult life situations. They offered her strength and an inner feeling that she could do or become anything, including overcome cancer.

1.2.7 Mary



Mary is a First Nations woman who was diagnosed with breast cancer in June, 2001 at 52 years old. Mary underwent radiation and talked of the importance of Aboriginal medicine, alternative healing and First Nations spirituality. Mary's story draws attention to how many Aboriginal women hide their First Nations spirituality and medicine from mainstream health care. When Mary was undergoing radiation she also used alternative medicines including her brother's hands on healing methods, herbs, and ceremonies, which she said cured her breast cancer and removed the negative effects of radiation. Similar to Shelley, the importance of nature: trees, rocks, and the natural environments were introduced through Mary's words and pictures. Mary has three children and five grandchildren and she works full time as an Aboriginal programmer. Mary said her family, children, grandchildren, Elders, healers, traditional friends and humour were essential in her emotional and spiritual healing.

1.2.8 Margaret



Margaret is a First Nations traditional Elder living on a Saskatchewan reserve who was first diagnosed with breast cancer in 1992, when she was only 23 years old. She talked about many repeated experiences with breast cancer and other illnesses. Margaret's story, like Mary's, draws attention to the importance of Aboriginal medicines and spirituality and the impact of hiding this from mainstream medicine. Margaret spoke of the power of dream visits by deceased relatives, natural healing, spiritual ceremonies and family and community members who cured her. She also spoke of shocking the medical system when her cancer miraculously disappeared. Margaret's stories were powerful in telling of colonial histories of Aboriginal peoples and the effect this has had on generations and its impact on health. She spoke of her own struggles, addictions, and inner strength to overcome them. Margaret is a healer in her community. She has two children and more than twenty grandchildren.

1.2.9 Tina



Tina is a First Nations woman who was first diagnosed with breast cancer in June, 2002 when she was 42 years old. She initially underwent both chemotherapy and radiation treatments but was diagnosed one year later with pre-cancerous cells and had surgery to remove her breast. Tina shared openly about how difficult the physical side effects of cancer treatments were on her, and how difficult it was to undergo surgery and become physically so different than how she saw herself. She was also scared that the physical changes would affect her relationship with her husband. Tina is married with five children and 8 grandchildren and she works full time in administration. She is a gentle and compassionate care-giver who spends time creating a beautiful home for her family. She hand paints her windows at Christmas and carefully crafts Christmas bags for each grandchild. Although Tina grew up in a white foster care family whom she appreciates lovingly, she felt very strongly about finding other Aboriginal woman breast cancer survivors. Like the other participants, she said that she was always looking for another Aboriginal woman while she was going through treatments and she wants to be there to help others.

1.2.10 Cheryl



Cheryl was first diagnosed with breast cancer in August, 2004 at 47 years old. She underwent both chemotherapy and radiation and has also survived cervical cancer. Cheryl described her Aboriginal ancestry as *the power of inner strength* and was the only participant who didn't feel that it was necessary to focus specifically on women of Aboriginal ancestry. Cheryl is a professional insurance broker and spoke at length of the failure of the government agencies such as Employment Insurance to assist financially when people experience long term illness. Cheryl, like Marjorie, Sandra and Dorothy, spoke quite powerfully about her trouble with financial worries. Cheryl said financial difficulties were more difficult than going through cancer treatment. Cheryl has two children, two grandchildren, and similar to the other women, believes strongly in inner strength and the power of laughter and humour, especially in healing and being well. Every time I met with Cheryl we laughed a lot.

Two other women who did not want to be identified were involved in the first part of the study and completed the first interview. Both of these women focussed on the importance of relationships and family as a breast cancer survivor. One woman talked about the importance of strong family support. The other woman talked about finding strength from her abusive relationship to overcome her cancer, care for herself and rebuild her life. As mentioned, the stories of all of these women frame this dissertation.

1.3 Significance of the Study

A Canadian woman's risk of developing breast cancer in her lifetime is approximately one in eight and breast cancer is the most invasive of women's cancer and the second most common cause of cancer related death (Canadian Cancer Society, 2005). However, a woman's chance of surviving breast cancer has increased with advances in treatment and cancer detection (Clegg, Li, Hankey, Chu, and Edwards, 2002). Although Canadian cancer registries collect little statistical data across different racial groups (Wilkinson, 2007) incidence of breast cancer for Aboriginal women is said to be rising more quickly than for non-Aboriginal women (Canadian Cancer Society, 2005), and survival rates are poorer (Marrett, Jones and Wishart, 2004). The Canadian Cancer Society (2008) also warns that the fast increase of cancer incidence and lower survival rates amongst Aboriginal peoples is evidence that these rates will surpass the Canadian population unless preventive measures are taken, including increased awareness, education, support, early detection and screening.

Yet, there is an identified lack of research directed towards Aboriginal people's experiences on medical care satisfaction (Garroue et al., 2004), as well as the effect of ethnicity on cancer experiences and survivorship (Ashing et al., 2003; Lopez, 2005a). Cancer care and survivorship experiences are said to be "heavily influenced" by social norms and values influenced by race, gender and class (Hewitt, Breen and Devesa, 1999; cited in Lopez et al., 2005a; Wilkinson, 2007) yet experiential research here is infrequent (Gill and Feinstein, 1994; Leedham and Ganz, 1999; cited in Lopez, 2005b). 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 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 is a culture thing, we don't want to hear it" (Mitchell et al., 2005).

More broadly, research in the area of Aboriginal health focuses on issues of identity, improving health and healthcare, emphasizing the intersection with colonization and the importance of self-determination (Assembly of First Nations, 2005). Health and healing is viewed as a consequence of the interrelatedness between historical, cultural, economic, environmental, psychological, physiological and spiritual factors (Waldram et al., 1995; 2006). Concepts of health and healing for Aboriginal peoples include interconnectedness, balance, holism, within the context of family, environment and community (Ellerby et al., 2000). The Saskatchewan Aboriginal Women's Health Research Committee (2004) attests that traditional healing systems and health care autonomy are part of revitalization of healing for Aboriginal women.

My dissertation 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 (Gill and Feinstein, 1994; Leedham and Ganz, 1999; cited in Lopez et al, 2005a). I combine the new empowering methodology of photovoice, with the more traditional methodologies of focus groups and interviews, to develop a contextual understanding of the meaning of breast cancer for Aboriginal women. Specifically, I explore Aboriginal women's experiences of breast cancer and social forces which influence breast cancer experiences. My research: 1) contributes to the growing knowledge of the link between social justice and health inequalities; 2) addresses gaps in Aboriginal health and breast cancer literature; and 3) provides a critical appraisal of cross-cultural research.

The original research study and the foundation for this dissertation was entitled: *Visualizing Breast Cancer: Exploring Aboriginal Women's Experiences* (VBC) and was completed by myself and two other researchers; Roanne Thomas-MacLean and Jennifer Poudrier. The research and this dissertation were 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 Region.

1.4 Overview

My dissertation shares the stories of twelve Aboriginal women living who live in Saskatchewan and who are breast cancer survivors. I use the term 'Aboriginal' to be inclusive to all of the women whose stories frame these pages. The term Aboriginal peoples refers collectively to Métis, Inuit and First Nations and follows terminology used

by the Royal Commission on Aboriginal peoples (Waldram et al., 2006: xi). Given the incredible diversity of background and experience of Aboriginal women across Canada and Saskatchewan, I do not pretend to offer an Aboriginal woman's perspective—no such exclusive perspective can possibly exist. My approach is to show the complex processes of how these Aboriginal women navigate their experience of breast cancer. Through listening to their stories, I learned that these women shared diverse experiences of fear, fear of recurrence, isolation, problems with social support, shifting identities, pain, early menopause, body satisfaction and dissatisfaction, well-being, confusion, wisdom, laughter, strength, resilience and hope—and all of these themes are, at least briefly, addressed herein. The narratives I spend the most time developing are the ways that their stories shift by the interrelated influence of gender, race, class, history and geographical space—and how these social forces shaped and limited the resources and survival strategies available to them. The women's stories must be situated and understood in this context. Towards this end, this thesis is divided into eight chapters outlined here.

In Chapters 2 and 3, I provide a literature review and a synthesis of relevant theories. Since my aim is to unfold the women's stories in layers, demonstrating the complicated link between the women's individual experiences and the social forces within their lives, this must be done parallel to the unfolding of the theoretical literature on health and social justice. There is an abundance of epidemiological and critical sociological literature which documents the impact of gender, class and race on health. I introduce these theories in Chapter 2 and document how they correspond to the women's stories throughout the dissertation. In addition, I introduce how the critical theories of governmentality and political economy help to frame the women's stories within current

ideologies and relationships of power. Feminist and anti-oppressive paradigms are reviewed in Chapter 3. These theories criticize epidemiological and critical theories for failing to account for the agency of individuals, and the anti-oppressive framework shows the importance of understanding layers of social forces, including race, class and gender. The introduction of feminist and anti-oppressive theories helps to uncover another layer embedded in the stories of the women which are also developed throughout the dissertation.

My approach, broadly framed, suggests that combining critical theories (insights from governmentality and political economy) and anti-oppressive theories (especially postcolonial feminism) provides important lenses to study Aboriginal women's voices and pictures, and these women's experiences of breast cancer in Saskatchewan. Anti-oppressive theoretical approaches reinforce the intersection of gender, race and class on breast cancer survivorship experience. Postcolonial feminism, in particular, means that we draw 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. The new theory of governmentality combined with political economy frames the women's experiences within current structures of power and new forms of governance.

Subsequently, in Chapter 4, I evaluate the use of the new qualitative research methodology of photovoice in connection with more established methods of qualitative data gathering, namely interviews and focus group discussions. This chapter provides a critical appraisal of cross-cultural research, using the photovoice method with Aboriginal women. Photovoice is defined as a participatory action research method, as well as a process towards health promotion. Participants take pictures to document their realities

and engage in critical reflection individually and in a group process, using images and stories to advocate community and policy changes. This chapter focuses on some of the methodological challenges and accomplishments associated with photovoice and the research project entitled *Visualizing Breast Cancer*. I discuss our team's collective successes as well as some of the responsibilities and risks of conducting research with Aboriginal women, including recruitment, participation, retention, community-building, advocacy and ethics. Interpretive boundaries and the "truths" of qualitative research (relative to the research setting) adds a further appraisal of the complexities of this type of qualitative research and the powerful lessons of research and unplanned happenings.

In Chapters 5, 6 and 7, I present the women's stories, beginning with their own words and pictures. My interpretation of the women's stories focuses on three core themes which I explore in Chapter 5, 6 and 7 respectively. These are: 1) psychological and physical role adjustments; 2) the importance of support; 3) identity and cultural safety. My main findings in Chapters 5 and 6, reinforce the importance of studying the intersection of gender, race and class on survivorship experience. The framework that emerges reveals noticeable social forces, namely: race and racism; class and socioeconomic situations; gendered role expectations; geographical space (rural, urban, on reserve); and historical and cultural experiences of Aboriginal women. These social forces affect a woman's ability to adjust to her physical and psychological experiences and to secure/garner safe social support related to cancer survivorship. In each of these chapters I move from the particular experiences of the women to their own analysis of the social context and draw links to socio-oncology, epidemiological, sociological and feminist literature. The focus of Chapter 7 is less about who the women describe themselves to be, and focuses specifically

on how they have been treated. I show how social forces shape the ways women are treated and how this affects their psychological adjustment to breast cancer and their support needs. In Chapter 7, I specifically apply the anti-oppressive theory of postcolonial feminism and the concept of cultural safety, and argue that this provides an important theoretical lens to assess the women's treatment in the context of colonial histories.

Finally, Chapter 8 is divided into two parts. First, I summarize key themes, the recommendations for future research and policy which evolved from the research and what has happened since. The second part of this chapter concludes the dissertation and situates the research findings and the research method in the context of historical, social, political and economic inequalities discussed throughout. The recommendations from the women and themes addressed are contextualized in current structures of power and domination. This final section provides caution towards proceeding with photovoice methodologies. I caution that there is a very real threat that photovoice research may reify mainstream stigmatizing/culturalized images of Aboriginal women, which risks alienating them from available support and health care services. In the end, I aim to raise awareness, to celebrate diversity, and to develop cross-cultural understandings of breast cancer survivors.

Chapter 2 “No Doctor can tell me what to eat...I am hungry.”³: Towards a Critical Understanding of Health Inequalities

The greatest analytical ‘mileage’ may be produced by stitching together insights garnered from differing theoretical perspectives (Anderson, 2004; cited in Browne, Smye and Varcoe, 2007: 136).

Aboriginal women’s experiences of breast cancer are stories of social injustice and social control. Following the voices and visual images of the women leads to questions of substantive equality between subgroups in society. In the following two chapters, I argue that literature on social determinants of health (social epidemiology) as well as theoretical models which address social inequalities and social forces (political economy and governmentality) and human agency (feminism and anti-oppressive theories) provide key insights and posit questions essential to contextualize the women’s stories and visual images. These two chapters rationalize combining critical and anti-oppressive theories by demonstrating that health/illness, Aboriginal women’s experience of breast cancer and the potential of empowering methodologies like photovoice are best understood through acknowledging their links to complex structural and governing processes (political economy and governmentality), while carefully understanding the intersectionality of oppression and agency (anti-oppressive theory).

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 (Bolaria, 2009). The knowledge of these links provides an initial lens to understanding the stories of Aboriginal

³Kleinfield, 2006: A20; cited in Cockerham, 2007: 15

breast cancer survivors. Aboriginal peoples continue to suffer social and economic inequalities, linked to histories of cultural genocide and colonization. Although social problems concerning Aboriginal peoples have been linked to historical trauma, physical health is not as consistently understood in relation to social-political contexts. Failure to address these underlying social forces has led to inadequate explanatory frameworks (Mitchell and Maracle, 2005), and it is for this reason that I argue that they are important here.

There is an abundance of social epidemiological and sociological literature which identifies causes of disease and death and experiences of health inequalities as linked to social conditions—related to, for example: race and racism; class and socio-economics; social support; socially produced stress; and cultural contexts (see, for example, Auger et al., 2004; Bolaria, 2009). Conservative social-epidemiological literature, however, tends to focus on individual behaviours and social-determinants as causal variables, overlooking the link to structural explanations and historical forces. In this chapter, I therefore review both the literature on social determinants of health as well as the sociological understandings of inequality and health thereby illuminating insights into the ways class, gender and race affect health.

In part one of this chapter, I address the social-epidemiological literature and the determinants of health, including: 1) socio-economics and class; and 2) ethnicity/race, racial harassment and racism. In part 2, I provide an overview of sociological theory, including 1) Marxism and the political economy and 2) Foucault and governmentality. These sociological theories locate social determinants of health within the context of: colonial and capitalist economic arrangements, colonized health policies—refutation of

traditional holistic models of health and on reserve conditions (political economy models), governing and new models of citizenship and governmentality. I link these theories to the overall theme of the dissertation, which is the importance of locating Aboriginal women's breast cancer experiences within colonial histories and social justice concerns linked to race, class and gender. As such, the difference between the approaches are identified by their varying definitions of social "justice".

The analysis of Aboriginal women's experience of breast cancer stitches together key insights from these diverse theories, even though the resulting framework identifies political economy, governmentality and anti-oppressive theory as providing the most essential lens.

2.1 Social Epidemiology and Social Determinants of Health

Poverty, the extent of relative deprivation, and the processes of social exclusion in a society have a major impact on the health of its population. All over Europe, in richer countries as well as poorer ones, those people who are worse off in socio-economic terms have worse health outcomes and higher death rates than those who are better off. (Shaw, Dorling and Smith, 2006: 196)

Social-epidemiology goes beyond biological understandings of medical knowledge. Illness and health are contextualized within cultural, social and economic locations. The social distribution of human health, illness and death are linked to material and social conditions. This literature introduces key concepts which parallel the women's stories and is essential in understanding Aboriginal women's experience of health and breast cancer. My focus in this first section is on literature addressing social factors related to class and race. Other relevant topics studied within social-epidemiology include: "economic cycles, socially produced stress, production processes, and working conditions" (Auger et al., 2004; Lynch, 2000; Lynch et al., 2000; Navarro, 1986; Smith, 1981; Waitzkin, 1983; cited

in Bolaria, 2009: 11). Because race, racism, class and socio-economic status are themes emerging from the women's stories, I address these as the more salient issues.

2.1.1 Health, Class and Socio-economics

Listen, if I want to eat a piece of cake, I'm going to eat it," she said. "No doctor can tell me what to eat. I'm going to eat it, because I am hungry. We got too much to worry about. We got to worry about tomorrow. We got to worry about the rent. We got to worry about our jobs. I'm not going to worry about a piece of cake." (Kleinfield, 2006: A20; cited in Cockerham, 2007: 15).

Scholars address relationships between class inequalities and the effect on health status (Vallgarda, 2008; Cockerham, 2007; Beckfield, 2004; Bolaria and Dickinson, 2009). Cockerham (2007: 75) argues that socioeconomic status and social class is "the strongest predictor of health, disease causation, and longevity in medical sociology." Marmot (2004; cited in Cockerham, 2007) argues that the risk for HIV-related diseases, heart disease, stroke, kidney, suicide, violent and/or accidental deaths increases with lower socio-economic status. Link and Phelan (2002) broadly define their fundamental social causes approach as an individual's ability to avoid illness through access to resources such as power, social connections, knowledge and socio-economic status.

Inequalities have important implications for peoples' lives especially in a highly stratified society. Social epidemiological work challenges policymakers to recognize that social conditions and inequalities are the fundamental social cause of disease. Bolaria and Bolaria (2009), for example, argue that poverty often translates into malnutrition, hunger, dependencies on food banks, homelessness which often leads to ill health and shorter life expectancies (Bolaria and Bolaria, 2009). Resources such as money, power and knowledge, embodied by higher socio-economic status are also argued to allow some people to avoid

risks of death and disease more than others (Cockerham, 2007). Socio-economic inequalities link to material factors such as diet, smoking and access to methods of problem solving and protective strategies (Cockerham, 2007). Avoiding contaminated water sources, poor hygiene, and improving diet can minimize health risks. The knowledge and ability to avoid these risks are related to resources connected to socio-economic status (Link and Phelan, 2000; 2002).

A number of recent studies demonstrate the effect of class position on health outcomes. For example, Lutfey and Freese (2005) researched diabetic patients control over their blood sugar levels showing that those with higher socio-economic status were better able to control their blood sugar levels and their survival prospects were also better. Phelan et al. (2004) provide evidence that those with higher social status are better able to use resources available to avert causes of death viewed as ‘preventable.’ Those lower on the socio-economic scale more frequently died of ‘preventable’ causes.

Cockerham (2007: 76 - 77) shares a story of an architect, a utility worker and a hotel maid who all suffered heart attacks—arguably a “preventable health outcome.” The *New York Times* (Scott, 2005: A1; cited in Cockerham: 2007: 76) reported:

Architect, utility worker, maid: heart attack is the great leveller, and in the first fearful moments, three New Yorkers with little in common faced a single common threat. But in the months that followed, their experiences diverged. Social class—that elusive combination of income, education, occupation and wealth—played a powerful role in...[their] struggles to recover.

The architect was rushed to a better hospital, received close monitoring (his brother who was the chairman of the board at another hospital asked for this “professional courtesy and his brother in law, who was a surgeon ensured he saw a “top specialist for follow up care” (Cockerham, 2007: 77.) His after care allowed him months off work, a top exercise

club close to home and supportive follow-up care. The maid, by contrast, was rushed to a hospital for the poor where she waited for two hours to see a physician. She experienced problems with health insurance, which she had to address by herself using public transportation. She tried a diet, but her husband was not able to change his eating habits so she gave it up. Her employer refused to let her work part time and she was soon back to full time hours, put her weight back on and her blood pressure and cholesterol rose to levels considered dangerous.

Social epidemiological health literature often defines the difference between absolute poverty and relative poverty leading to ill health and health inequalities (Link and Phelan, 2000). There is evidence that income inequalities are a predictor of life expectancies in industrial nations (Moore, 2006; Wilkinson 1992). Link and Phelan (2000) argue that this evidence may help to provide indication that an absence of power and control becomes a factor in health and longevity. Explanations of modern risk associated with relative poverty also focus on the stress associated with lower positions within a societal hierarchy. This stress is argued to have indirect ill-effects on health habits such as sleeping too little, consuming alcohol, drugs, cigarettes, eating too little or too much, and more. For example, research in the U.S. reports that people with a high-school education are three-times more likely to smoke than those with a bachelor degree or higher (Cockerham, 2007). Similarly, research in England has shown that those in managerial and professional occupations are less likely to smoke than those in routine and manual occupations (18 and 33 percent of men respectively) (Cockerham, 2007). If we reduce individual risk factors, such as smoking (or alcohol, etc.) to personal choices this involves “blaming the victim” and fails to account for social conditions shown to reinforce these

behaviours. The social factors associated with socio-economic status such as stress, deprivation, socialization and social networks are thereby linked to behaviours such as smoking, eating habits and addictions (Jarvis and Wardle, 1999). Relative poverty, deprivation and the experience of marginalization is important in understanding these behaviours and health inequalities.

On the other hand, social support and affiliations are included as *protective* strategies to lower health risks and are associated to socio-economics (Wilkinson, 2006; Mansyur, Amick, Harrist and Franzini, 2007). Relationships within community and friendship networks, especially close confiding types of friendships and support, are argued to benefit health outcomes. "...confirming these connections, hostility and 'negative' relationships have been shown to be harmful to health" (Stansfeld et al., 1997; cited in Wilkinson, 2006: 342). The level of society and social cohesion also has an impact on health:

It is important to recognize that many economic and fiscal policies may influence the social cohesion of a society. Those policies that increase income inequalities are likely also to increase health inequalities. On a slightly smaller scale, the design of the built environment may also influence possibilities for social interaction which may subsequently influence health. (Stansfeld, 2006:166)

As it relates specifically to breast cancer, much of the Canadian literature on class, socio-economics and breast cancer remains epidemiological and there continues to be relatively fewer studies on lived experience (see, for example, Thomas-MacLean, 2005; Wilkinson, 2007). For example, a Canadian survey distributed to breast cancer survivors reveals that fifty percent have encountered some financial need throughout their treatment and diagnosis (Kasper, 2000). Kasper (2000) also reveals that the loss of income related to cancer treatment and the stress related to finances have a more profound impact on women

with lower socio-economic status. There is also research which suggests that mortality rates due to breast cancer are higher for lower-income women (Lannin, Mathews, Mitchell, Swanson, Swanson, and Edwards 1998; Macleod, Ross, Gillis, McConnachie, Twelves, and Watt 2000; cited in Gould 2004). Mackillop et al., (1997) argued that women with household incomes less than \$20,000 have a five year survival rate of 64 percent. They compare this to women with household incomes which are over \$50,000 who have a five year survival rate of 76 percent.

The link between social determinants and diseases such as HIV/AIDS and breast cancer become more apparent over time (Link and Phelan, 1995). For example, as information about prevention and transmission of HIV and AIDS is more available, associations of occurrence with socio-economics becomes more apparent, perhaps stronger. In the HIV/AIDS literature, those who are more disenfranchised are now at more risk of transmission (Link and Phelan, 1995). With breast cancer, although rates of survival are better overall, they are worsening for some groups—such as African American women in the United States and Aboriginal women in Canadian society (Hannah, 2007). This has been 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.

This social-epidemiological literature poses important questions for this *Visualizing Breast Cancer* research on the impact of social conditions and socio-economic inequalities on the women's lives. 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 (Frideres, 2009). Shah (2004) provides a powerful example of this research.

The socio-economic environment, indicated by education, employment and income, is an important predictor of the health status of a population. In 1996, 54 percent of the Aboriginal population, compared with 35 percent of the non-Aboriginal population had not completed high school...Among First Nations people living on reserves, the unemployment rate was ...triple the national unemployment rate. 46 percent of First Nations people on reserves rely on social assistance, a rate four times higher than the general Canadian population...on and off reserves, relative homelessness has been well documented by government and other sources including the Royal Commission on Aboriginal peoples (Royal Commission on Aboriginal Peoples, 1997; cited in Shah, 2004: 269-270).

Some of the highest poverty rates in Canada are amongst Aboriginal peoples (Ross, Scott and Smith, 2000). Concerning youth: one in four First Nations children are living in conditions of poverty; high school graduation rates are 50 percent of the Canadian rate; Aboriginal children are over-represented in child welfare systems and First Nations youth commit suicide at a rate five to eight times higher than the Canadian rate (PSAC, 2008). Poverty and violence against Aboriginal women are also high. Average annual income for Aboriginal women is \$13,000, compared to over \$19,000 for non-Aboriginal women and over \$18,000 for Aboriginal men (PSAC, 2008). Amnesty International and NWAC have shown that Aboriginal children and women remain susceptible to violence and poverty linking this to government policies of separation from traditional support, including forcing Aboriginal children away from their families into residential schools and the removal of Aboriginal women's status if they married a non-Aboriginal man. The rate of intimate partner violence is over three times that of the national Canadian rate (PSAC, 2008). Hundreds of cases of Aboriginal women who have been murdered or who are missing in the past two decades have been left not fully investigated (Amnesty International, 2004).

Beverley Jacobs, the president of the Native Women's Association of Canada stated: "The high levels of racialized, sexualized violence directed against Aboriginal women in Canada is a national and international shame" (NWAC, 2008; cited in Amnesty International, 2008). Many Aboriginal people also suffer from insecure living situations. Problems with housing include severe overcrowding, disrepair and lacking basic necessities. Other related problems are a lack of income for quality foods and difficulty accessing medical services and consumer goods.

In the *Visualizing Breast Cancer* research, the women spoke of financial concerns related to: supporting their families; on reserve living; housing and homelessness; loss of work as a result of their breast cancer; related violence against them; problems with government programs such as social services, Employment Insurance (EI); and a general lack of programs in place for financial support during illness.

Many of the *Visualizing Breast Cancer* participants' stories also reflected socio-economic concerns that were specifically related to being Aboriginal women. I therefore argue that the social epidemiological literature related to race and gender also puts forth relevant and key ideas such as attention to the effect of racism, social, and economic disadvantage. .

2.1.2 Ethnicity, "Race" and Health Inequalities

Although the issues affecting Aboriginal populations can be analyzed at the aggregate level, it is equally important to consider how the collective burden of a history of discriminatory practices, and economic and political marginalization, continue to exert their effects at the individual level and in local contexts (Adelson, 2005; cited in Browne, 2007: 2166)

Health differences and different rates of morbidity and mortality are evident across race and ethnic groups (Nazroo and Williams, 2006). This has been documented repeatedly

throughout Canada ,the United States, South Africa, Latin America, Australia and more (see, for e.g. Health Canada First Nations and Inuit Health Branch, 2003; Shah, 2004; Pederson and Raphael, 2006; Frideres and Gadacz, 2008). Although death rates for Aboriginal peoples are more similar to non-Aboriginal peoples than historically (the death rate of Aboriginal peoples was more than double non-Aboriginal peoples in the 1980s and has decreased by nearly one-half today), the age group from 15 to 44 continues to have a mortality rate double that of the average Canadian (Frideres and Gadacz, 2008). Also, the incidence of cancer, suicide, chronic illnesses such as tuberculosis and diabetes, respiratory and circulatory diseases are “much greater” amongst Aboriginal peoples than non-Aboriginal peoples in Canada (Frideres and Gadacz, 2008: 81). Rates of HIV/AIDS amongst Aboriginal peoples reflect these recent statistics.

Unlike the general population, where the number of AIDS cases has levelled off, the number of AIDS cases among Aboriginals has dramatically increased over the past two decades. From 1998 to 2001, over one-fourth of all reports of HIV-positive tests were from Aboriginal people... Today we find the proportion of AIDS cases among Aboriginal persons has climbed from 1 percent of all cases in Canada before 1990 to over 7 percent in 2002 (Frideres and Gadacz, 2008: 84).

While Aboriginal peoples cancer rates are historically low, these are increasing dramatically for some cancers in some regions. Preventable cancers are said to be on the rise (Marrett, Jones and Wishart, 2004). As I outlined in the introduction breast cancer shows similar trends. Canadian women have a one in eight chance of being diagnosed with breast cancer and for Aboriginal women the number is said to be higher, although the exact amount is not available (Status of Women Canada, 2005). Survival rates from cancer and breast cancer are also lower in Aboriginal populations compared to non-Aboriginal populations (Marrett, Jones and Wishart, 2004). According to Health Canada (2005):

“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” (cited in Hannah, 2007: 6).

Explanations of health inequalities that discuss race and ethnicity vary from biological-determinism and genetics to discussions of structural racism and links to socio-economics and histories of oppression. Importantly, some argue that understanding both genetic/bio-medical factors and socio-cultural and environmental conditions are important (Poudrier, 2003). Explanations which rely solely on genetics are critiqued because of the risk of reinforcing stigmatization/oppression of racial minorities and focussing all of the resources on bio-medical solutions negating essential health building strategies such as ensuring good food, pure water, social housing and safe environments (Poudrier, 2003).

There are a myriad of epidemiological research studies which continue to view race as biological and genetic, and ignore class-related causes and the impact of racism. Genetic and cultural elements are said to be related to ethnicity and are linked to health inequalities: “...historically, race, genetics and disease have been inextricably linked, producing a calculus of risk that implicates race with relative health status.” (Lee, Mountain, and Koenig, 2001: 58; cited in Pederson and Raphael, 2006: 174). Genetic causes of diseases amongst certain “ethnicities” or “racial” groups, is expanding in current medical research, towards pharmaceuticals (custom made for certain “racial” groups), medical development and screening towards genetic predisposition (Poudrier, 2003). Poudrier (2003: 122) states: “the link between “race” or “ethnicity” and genetic susceptibility has become an extremely lucrative area of medical research.” There are many problems with an analysis which links race to genetic categories—including Zwillich’s (2001; cited in Poudrier, 2003) argument

that there is more variation between genetics of people within (socially constructed) racial categories than those in racial categories considered “different.” A sociology of knowledge perspective argues that scientific genetic explanations have risen to satisfy certain social concerns and racist assumptions. Poudrier (2003: 122) explains:

In the current climate where health care decisions are determined by ongoing fiscal crises, disease is often problematized according to already marginalized groups with racial categories...heritability and genetic “fitness” are social constructions emerging out of the already well-established social order that continues to perpetuate the ideology of problematic “races” with problematic diseases.

In other words, social concerns, not genetic evidence are the driving force of genetic explanations. (Duster, 1996; cited in Poudrier, 2003). Further, critical research teaches that biological “race” categories are not valid, which means that medical and genetic evidence of “racial” distinctions may reinforce deterministic views which risks reinforcing racist assumptions and practices such as eugenics (Wertz, 1998; cited in Poudrier, 2003); “... categories of racial distinction, constructed through the scientific process (and ironically through the ideal of scientific progress) may become more firmly substantiated as scientific fact” (Poudrier, 2003: 123).

Critical race scholars point to race as socially constructed and argue that racism within society and health care doubly marginalize the health experiences of minority peoples (Frideres, 2009). Race is a social not biological term and refers to superficial physical characteristics and socially constructed hierarchies (Smaje, 2000). “...the concept of race has been linked historically with slavery and the colonial relationships between Europe, Africa, and the Americas that were accompanied by a racial ideology used to justify the unequal treatment of people defined as inferior by individuals and social institutions” (Oliver and Muntaner, 2005; cited in Cockerham, 2007: 140). There is

consensus in the social sciences about the social construction of race and ethnicity and that this represents social control/power by dominant groups over minorities (Pederson and Raphael, 2006). As we saw above, however, health researchers do not always share this position—“for them race and ethnicity are indicators of biological disposition to disease or a convenient marker to identify targets for public health interventions (Cruickshank et al., 2001; cited in Pederson and Raphael, 2006: 173).

Definitions of racism in the social sciences extend from “a system of advantage based on race” (Wellman, 1977), to “prejudice plus power” (Rothenberg, 2007: 126). The former includes racism as personal ideology/prejudice, beliefs/practices, as well as a critique of systems of institutional/cultural messages, policies and systemic practices (Wellman, 1977; cited in Rothenberg, 2007). “Prejudice plus power” includes a critique of social power, institutionalized racial practices/policies and access to economic, social and cultural resources/power. Definitions of racism now more frequently consider the concept of “white privilege” (McIntosh, 1989; Rothenberg, 2008), which is a critique of systemic privileges associated to being white—even amongst rhetoric of “reverse racism” and “affirmative action.” Rather than exclusively focussing on racism, literature on white privilege includes ways people/groups benefit from institutionalized racism, inadvertently and/or deliberately. This literature offers means for those with privilege to challenge systemic racism—by using their power derived simply through whiteness (McIntosh, 1989; 2008; cited in Rothenberg, 2007; 2008):

Of course she enjoyed greater access to jobs and housing. But she also was able to shop in department stores without being followed by suspicious salespeople and could always find appropriate hair care projects and makeup in any drugstore. She could send her child to school confident that the teacher would not discriminate against him on the basis of race. She could also be late for meetings, and talk with

her mouth full, fairly confident that these behaviours would not be attributed to the fact that she was white. She could express an opinion in a meeting or in print and not have it labelled the “white” viewpoint. In other words, she was more often than not viewed as an individual, rather than as a member of a racial group. (McIntosh, 1989; cited in Rothenberg, 2007: 126-127).

Structural and institutional racism, which plays a role in economic and social disadvantage, is viewed as centrally connected to unequal health outcomes (Nazroo and Williams, 2006; Conley, Strully and Bennett, 2003). There is a very large body of knowledge that links racism to health problems (Nazroo and Williams, 2006; McKenzie, 2003; Gill, Bhopal, McKenzie and Kaul, 2003; Bhui, Stansfeld, McKenzie, Karlsen, Nazroo and Weich, 2005; Karlsen and Nazroo, 2002; Gilbert, 2002) Authors here show connections between health outcomes, race and socio-economic marginalization. Health outcomes are linked to shared experiences of racism and discrimination, which are seen as part of the everyday lives of racial minorities, including living with harassment and fear.

Authors such as Galabuzi (2005; 2006) argue that ethnic inequalities in health are determined by socio-economics. There is extensive research outlining material conditions of minority groups as social determinants of health inequalities. This includes research on poverty, employment, income, housing, recreational opportunities, nutrition, conditions of work and more.

Wilkinson (2006) connects the broader social structural conditions of racism to psychosocial health risk factors and inter-personal environments. This literature examines, for example, the social importance of our self-consciousness and how we appear to others. Wilkinson’s (2006) evidence details how MRI scanners display the deeply aversive impact of social exclusion. “A recent experiment using an MRI scanner has ... found that the pain of social exclusion activates the same parts of the brain—the anterior cingulate cortex and

right ventral prefrontal cortex—as physical pain does” (Lieberman, 2003; cited in Wilkinson, 2006: 345). Wilkinson (2006) argues that this provides evidence of the importance of examining social status, affiliations, income differences, racism and social corrosion.

What makes us socially malleable and provides the basis for socialization and conformity is the importance of how we appear to others and our capacity for shame and embarrassment...so is the route through which society gets under the skin to affect health...it is because we are so sensitive to the eyes of others that pride and shame, acceptance and rejection, social inclusion or exclusion have such powerful influences on stress (Wilkinson, 2006: 345).

Social epidemiological explanations also combine economic with social inequalities to health of ethnic minorities (Nazroo and Williams, 2006). Social inequalities include discrimination, perceptions of discrimination, racial harassment—which are identified as markers of stress which increase outcomes of disease:

...a large body of convincing evidence now supports the possibility that ethnic inequalities in health are largely a consequence of socio-economic differentials. This applies across a range of ethnic minority groups and a range of outcomes. In addition, there is a growing body of evidence suggesting that experiences of racial harassment and discrimination, and perceptions of living in a discriminatory society, contribute to ethnic inequalities in health (Nazroo and Williams, 2006: 259).

In much of the literature on racism and health, structural and institutional racism, which plays a role in *economic* and *social* disadvantage, are viewed as centrally connected to unequal health outcomes (Nazroo and Williams, 2006; Conley, Strully and Bennett, 2003).

The literature on racism and health inequalities provides important questions for the present study on the impact of racial discrimination, prejudice and systemic racism on the women’s health experiences. Social-epidemiological literature on race asks

questions on how racism shapes identity, self-consciousness, support, behaviour and marginalization.

2.1.3 “Social Justice” and Social Epidemiology

The goals of social epidemiological research reach beyond theoretical and conceptual clarification. Social epidemiological research also aims to enhance the health of populations (Ward, 2007). It seems clear that understanding risk factors related to cancer, poverty, smoking, support networks, obesity and racial discrimination (to name a few of the examples cited above) may contribute to better health outcomes. Social epidemiological researchers commonly define social justice within individual frameworks, articulating how to assist individuals reduce risk. Prescriptions for social justice often lie in empowering or enabling disenfranchised and marginalized peoples to adopt healthier behaviours and attend to economic and social programs which may enhance or encourage healthier choices and behaviour (Ward, 2007).

There is also much social epidemiological work, however, which argues that individual level variables are not enough without also addressing unhealthful forces in society. Social epidemiology is more readily addressing structural variables which are also detrimental to peoples’ choices and health (Ward, 2007). Syme (1994; cited in Ward, 2007: 465) for example, writes that “just as bad water and food may be harmful to our health, unhealthful forces in our society may be detrimental to our capacity to make choices and to form opinions”. This on-going work in social epidemiology draws on a more fundamental cause approach in an attempt to identify “unhealthful forces” as causing unequal outcomes in health (Ward, 2007: 465).

Authors here, however, argue that this movement within social epidemiology requires a more theoretically grounded analysis of fundamental cause. Ward (2008: 465), argues, “without a clear, theoretically precise and well-grounded understanding of the characteristics of fundamental causes, there is little hope in applying the statistical tools of the health sciences to hypotheses about fundamental causes, their outcomes, and policies intended to enhance the health of populations”. The definition of social justice from the fundamental cause approach deepens beyond individual level variables, and is developing conceptually and theoretically.

I argue that social epidemiological research would benefit from consideration of social structural context as seen through the lens of sociological, feminist and anti-oppressive theories. In what follows, I introduce the relevant critical sociological literature and address relationships between health inequalities and fundamental causes stemming from class, race, gender, and sexuality.

2.2 Critical Theory: Political Economy and Governmentality

The political economy and governmentality perspectives provide a lens to deepen lines of questioning with the VBC research concerning social, economic, cultural, ideological and racial determinants of health. These perspectives together address privilege, injustice, collective rights and the role of government in relation to health care. Using both of these theories together allows me to question the shift from welfarism to neo-liberalism and the impact this has on inequalities and health.

In this dissertation, although I identify parallels with social epidemiological literature and the women's stories, the critical theory deepens my analytical lens. Applying these critical lenses, I contextualize the women's stories and pictures in relations of power and unjust social relationships. These perspectives also provide a critical lens to assess the potential of photovoice research and empowerment philosophies. To understand the women's lives as a social justice issue means that we move from the individual level of analysis offered by social epidemiology to a questioning of deepened relations of power offered by the critical theories.

2.2.1 Political Economy and Marxism

Human health and illness are embedded in economic, social and cultural contexts, and these factors play an important role in creating the social distribution of health and illness (Bolaria, 2009: 11).

The Marxist critique of the medical profession arose in opposition of the conservatism of Parsonian structural functionalism, which dominated medical sociology in the 1950s and the 1960s. The origin of this critique has been traced to European student revolutions in 1968, which is said to have legitimated topics of justice and inequalities for

medical sociologists (Lupton, 2003: 95). This political economy perspective emphasizes human rights and provides a critique of the ways that society is structured often in the interest of high-status groups, including the medical profession. This perspective combines the social and economic determinants of health and poses questions such as: “why do some people, groups, nations, or groups of nations have better health than others?...the unique point of view of political economy is that it focuses on the links between health and the economic, political, and social life of different people, regions or societies” (Coburn, 2006: 59).

The central paradox of medicine as defined by critical political economy/Marxist scholars is that medicine continues to amass power and influence despite “its alleged lack of effectiveness in treating a wide range of conditions and its iatrogenic side-effects” (Lupton, 1997: 95). The position of political economy and its relevance to the VBC research, can be demonstrated in five themes. This position argues 1) that medicine is hegemonic (Bolaria, 2009). The medical focus on individual curative measures obfuscates the social, economic and political determinants of health. This medicalization critique is extended to understand 2) gender; and 3) race and power differences between medical professionals and patients. This Marxist critique also demonstrates vested interests within the medical industry placing “profits” over people’s health. Proponents of the Marxist approach generally criticize members of the medical profession and medical industrial complex (including pharmaceutical companies and medical suppliers) for their exclusive rights to treat and to define illnesses and subordinating lay peoples’ knowledge of their bodies and health—creating profits. I conclude this section by 4) defining social justice, emancipatory ideals from Marxist perspective, and 5) its critique.

2.2.2 Medicalization and the Medical Industrial Complex

The political economy of medicine as hegemonic provides a critique of health strategies that are bio-medical, individual and technical in nature and for obscuring the social malaise (Lupton, 1997). This perspective argues that social determinants of health (as discussed above) associated with ill-health such as stress, nutrition, support systems, information and environmental factors are shaped by socio-economics, institutional racism and gendered social relations. Rather than address the root causes these strategies identify poverty, social problems and disenfranchisement as “risk factors” and intervene. By depoliticizing macro-structural problems we reinforce the same conditions that produce ill-health and personal suffering, the opposite of the intended effect (Poudrier, 2003). Lupton (2003: 96) summarizes the risk of the power assigned to scientific medicine: “This increasing power of scientific medicine, it is contended, has detrimental effects for traditionally disempowered and exploited social groups by deflecting questions of social inequality into the realm of illness and disease, there to be treated inappropriately by drugs and other medical therapies” (Lupton, 2003: 96).

This perspective questions the link between the market economy and the social construction of medical knowledge, medical expertise and treatment. Research here suggests the profit mode within medicine is dictating more and more medical practice (Clarke, 2000). For example, Cronon (1999) argues that new drug therapies are often promoted by manipulating statistics and research findings in the interest of marketing not health. Clarke (2000) states that 90 percent of the pharmaceutical and drug industries are owned by multinational corporations.

Research from the political economy draws attention to the “profit center” of cancer, which lies within prevention, detection and treatment. In relation to breast cancer, Zones (2000) argues that radiologists have had a financial interest in pushing mammography. Zones (2000) questions how private companies may exaggerate benefits of treatments to increase profits. Research discloses overstatements of the benefits around chemotherapy and the manipulation of statistics, including an elimination of participants with outcomes which do not support specific findings: “We learned...of research and treatment biases—e.g., length bias, which means that women whose tumors are discovered earlier appear to be living longer than women who are diagnosed at a later date; selection bias, which refers not only to preferential choice of subjects in a study, but also to elimination of participants from outcome statistics if they die during chemotherapy; and of doctors’ overstatement of the benefits of chemotherapy” (Zones, 2000; cited in Lemay, 2006: 188).

The difference between expensive technical research in bio-medicine versus calls for deepening the public health movement are also focussed on in the breast cancer literature (Zones, 2000; Lemay, 2006). Zones (2000) argues that pharmaceutical companies focus on individual examinations of women and mammography rather than community actions as the best prevention and protection against breast cancer. Zones (2000) and others argue that methods of prevention have a greater impact on breast cancer survival than bio-medical technical solutions including vaccination and penicillin. The public health perspective aims to eliminate causes of breast cancer, including environmental, social, nutritional and behavioural prevention methods. (Zones, 2000). This literature also draws attention to corporate opposition to these public health movements. Zones (2000), for

example, discloses information about pharmaceutical companies which produce herbicides and pesticides censoring material which was going to be used during Breast Cancer Awareness month, which they also sponsor.

Thus, political economy theorists critique medicine/medicalization as a medical industrial complex (Clarke, 2000):

The medical care system has become a medical-industrial complex and now includes the pharmaceutical industry, hospitals and long-term care institutions, and the medical supplies (e.g., from bandages to CAT scanners)...the system is administered by large bureaucracies: medical and hospital administrators, managers and planners, government health ministries, and local health units with jurisdiction regarding reportable and communicable diseases (Clarke, 2000: 298).

Multi-national corporations are making money at the expense of health, through the medical industry.

Although I continue my discussion of political economy and medicalization on race (below), the following section includes an introduction to how feminist writers incorporate the medicalization critique.

2.2.3 Feminism and Medicalization

Feminist theorists have argued that medicine is a patriarchal institution which has helped maintain women's lesser status. Research here emphasizes medicine as social control and has shown medical influence in defining women's roles and women's bodies:

The hierarchical nature of the doctor-patient relationship is obvious in medicine's portrayal of women as weak, fragile, and emotional creatures, and the physician as the expert with a monopoly of medical knowledge. Within this relationship compliance is expected. (Walters, 1994: 308).

Medicalization means that illness becomes defined as a physical or psychological "illness"—a problem for medicine. One of the most important critiques for women is that medicalization tends to individualize women's problems—which means that the fixing lies

within the individual and leaves patriarchal notions of “femininity” untouched (Berenson, Miller and Findlay, 2009). Patriarchal images of femininity, upheld in the medical industry, also help create a billion dollar industry in cosmetic surgeries. This includes a feminist critique of breast implants as becoming a normative response to breast cancer, which is also said to reinforce patriarchal and consumeristic images of female bodies.

Breast cancer advocates have been writing passionately about the medical view towards breast implants and the ideological standpoint about breasts in society—created through consumerism. There is anger in breast cancer activist words for having to put silicone in their bodies to feel that they can be “normal” female and sexual beings:

Where ‘normal’ means the ‘right’ color, shape, size, or number of breasts, a woman’s perception of her own body and the strengths that come from that perception are discouraged, trivialized, and ignored...where the superficial is supreme, the idea that a woman can be beautiful and one-breasted is considered deprived, or at best, bizarre, a threat to ‘morale’ (Lorde, 1997: 66).

Breast cancer reconstructive surgery is connected by some medical doctors as “not about cosmetics ...not about self-esteem...[but] is part of healing with dignity” (Shapiro, 2007; cited in CTV, 2007)). Belinda Stronach has launched “The Belinda Stronach Chair in Breast Cancer Reconstructive Surgery” which will provide two million dollars to fund advanced refined techniques for reconstruction, attract top surgeons and provide a visiting professorship program (CBC, 2007). The continued funding and non-questioned acceptance of reconstructive surgery and prosthetics is seen by Lorde (1997) as another way to keep survivors apart and social norms unchallenged:

...whether deliberate or not, silencing their bodies with an imitative device suppresses their voices as well...speaking a common, embodied language was dependent on not tidily covering up unpleasant or uncomfortable silences (Knopf-Newman, 2004: 120 - 121)

These authors link political and economic structures to compulsory “white heteronormativity and femininity” and discuss how these norms work against women’s healing from breast cancer (especially racial minority women). Additionally, links between covering up the loss of a breast are argued to be connected to covering up “carcinogenic materials” manufactured by corporations and sold to the public:

My scars are an honourable reminder that I may be a casualty in the cosmic war against radiation, animal fat, air pollution, McDonald’s hamburgers and Red Dye No. 2, but the fight is still going on, and I am still a part of it. I refuse to have my scars hidden or trivialized behind lambswool or silicone gel” (Lorde, 1997; cited in Knopf-Newman, 2004: 135).

Lorde (1997; 1980), not only draws attention to the ways that dominant cultural narratives dictated by political and economic greed and power distort women’s healing but suggest that political struggles are taken on by her own body—showing unclear boundaries between her cancer experience and societal inequalities embedded in race, sexuality and gender: “The layering of the silences she sought to extract from her body and other women’s bodies was as complex and dense as the layers of tissues beneath her flesh...the way in which people are taught to be silent about the pain in their bodies is not altogether different from the way in which people learn to ignore segregation and racist violence” (Knopf-Newman, 2004: 125). The importance of including race in discussions of health inequalities is evident in Lorde’s writing. Her focus drew attention especially to the dichotomy of black women’s perceived inability, yet true ability to take-up control of their own bodies.

Other critical authors include racism and historical colonization and neo-colonialism, towards shaping an understanding of the link to health inequalities for Aboriginal peoples in Canada, which is my next topic.

2.2.4 Medicalization, Race and Aboriginal People

The historical relations between Aboriginal people and the nation state—characterized by wardship, welfare colonialism, the creation of reserves, the appropriation of Aboriginal lands, the forced removal of children into residential schools, discriminatory attitudes towards Aboriginal people, and a continued lack of vision in terms of the effects of these relations—continue to exert their influence in terms of health, social, economic, and political disparities (Adelson, 2005; cited in Browne, 2007: 2166).

Aboriginal health and racial inequalities are linked to the dominant economic mode and ideological frameworks, which reproduced marginalization. Satzewich and Wotherspoon (2000: 179) argue that not only have socio-economic inequalities, colonized health policies and the refutation of traditional health models led to inequalities in health, but that life on the reserve and environmental conditions are also important factors to consider: "...the introduction and transformation of capitalist relations of production have had considerable impact upon both the health status of, and the provision of health care services for, Canada's Aboriginal peoples...there is a close relationship between the social and economic marginalization of Aboriginal peoples and the deterioration of their health conditions". Waldram, Herring and Young (1995; 2006) similarly discuss historical colonial policies and argue that assimilation, residential schools, criminalization of health practices such as the Sundance and Sweat Lodge, forced labour and the transmission of infectious disease, led to increased ill health and death of Aboriginal peoples. Frideres (1994; 2009) argues that policies of assimilation, colonization and institutionalized racism are important factors in understanding health inequalities for Aboriginal peoples and these are exacerbated by individual bio-medical approaches towards the treatment of illness and medicalization.

Bio-medical approaches can be problematic for Aboriginal peoples on a number of additional levels. Cause and treatment within the European perspective focus on individual curative orientations, whereby medical solutions solve immediate problems. As mentioned, from modern medical perspectives, social economic and political links to health and illness are forgotten. Bio-medical models treat symptoms and therefore may fail to address fundamental causes of poor health including poor nutrition, unemployment which is chronic, violence within communities, homelessness, and crowded living conditions. These are linked to a history of oppression, assimilation and exploitation of Aboriginal peoples.

Denial of fundamental causes, assimilation and exploitation of Aboriginal peoples and culture may further discriminate against and stereotype Aboriginal peoples within medicine. This contributes to worsening health, by decreasing meaningful support and increasing stress. Frideres (1994: 215) adds that: “the practitioners do not understand the attitudes and lifestyle of lower-class patients...Health-care professionals, socialized in a middle-class milieu with the modern medical ethic, are ill-prepared to deal with patients whose behaviour does not conform to middle-class values” (Frideres, 1994: 215). For example, if medicine is prescribed, the individual is required to purchase medicine, understand instructions and change their lifestyle (Frideres, 1994; 2009). This may be a problem for Aboriginal peoples who may not be able to purchase the medicine, and may not have adequate housing, access to automobiles, or eat regular meals or foods which reflect nutritional standards (Frideres, 1994; 2009). Further, some Aboriginal peoples have a more holistic perspective regarding health than is reflected in biomedical models: “Aboriginal people define health and illness in terms of balance, harmony, holism, and spirituality rather than in terms of the western concepts of physical dysfunction and disease

within the individual” (Kirby and LeBreton, 2002; cited in Shah, 2004: 267). The objective and rational scientific presence whereby there is an extensive division of labour, is foreign. Aboriginal patients may heal themselves and practitioners may stereotype them as “irresponsible, dirty and incapable of carrying out orders or taking responsibility for themselves” (Frideres, 1994: 215). Health care professionals’ middle class mentalities are argued to contribute to increased stereotyping of Aboriginal peoples. Behaviours of those outside of the middle class mentality are judged within medicine as less than desirable:

[Practitioners] assume that Native patients share their perspective on illness and health care, and that they have the same resources (or access to the same resources) as the middle-class patient or the medical professional. In reality, however, Native people are usually poor and can manage only the barest of material necessities: heat, food and clothing. Thus their desires are for material improvements—health is not a high priority nor is it considered in a specific sense. The day-to-day experiences of medical practitioners clearly reinforces the notion that Native patients do not follow their orders and heal themselves (Frideres, 1994: 215).

2.2.5 Social Justice and Political Economy

The critical political economy perspective understands knowledge as socially constructed and historically specific, in the interest of the dominant in society (Brooks, 2008). Knowledge is also hegemonic, having an ideological function which appears as “truth” (Brooks, 2008). Deconstructing knowledge claims, with the goal of exposing the interests which inform them is part of the struggle towards social justice.

To attain social justice from the political economy perspective means that we deconstruct the medicalization of social problems and develop a counter hegemony which recognizes structural roots and inequalities in health. The role of critical theories goes beyond deconstruction and theorization towards emancipatory claims for social change (Habermas, 1986; cited in Moosa-Mitha, 2005).

Social justice from this perspective links the right to safe environments, nutritious and safe food, clean water, social housing and movement to substantive equality in health, education, employment and living (Poudrier, 2003; Reiman, 2007). We will see these themes reflected in the women's stories and longer term desires. The focus on bio-medical, technical solutions and/or genetics are seen to divert focus and funding away from these essential health building strategies (Frideres, 1994; 2009; Poudrier, 2003).

These writings also reflect Marxist notions of equality and justice, and critique domination inherent in capitalist and colonial societies as the source of inequalities. Medicine, from this perspective, represents the interest of the more powerful group. On the basis of this writing, however, political and practical measures are suggested to transform a "one-dimensional society", where oppression results from the dominant in society, (Pavlich, 2000: 54) and this is subject to much critique.

2.2.6 Marxism and the Critique of the Emancipatory Ideal

The Marxist political economy perspective has been identified as in crisis since the end of the 1980s, especially because of the "judgemental critique" (van-Swaningen and Taylor, 1994: 183). There is no question that the radical challenge towards structures of injustice, medicalization and depoliticizing of political, economic and social problems (and propositions of human rights) are powerful. However, this level of critique has and continues to privilege authoritative judgement above other discursive techniques and times have changed. Lyotard (1984; cited in Pavlich, 2000: 60) argues that "this raises important questions for the plight of such criticism in truth regimes that problematize the authority of expert or critical judgement."

Zygmunt Bauman (1995) defines postmodernity as the declining role of the state and state institutions and the recognition that the market manages the co-ordination of society. Citizens follow rules not because we are citizens of the state but because of the seductive promise of consumerism. Pettigrew (1996) describes this as a process of regulation that is based on envy, self-interest, competitions, consumerism and endless production. What feeds the new global market therefore are the abstract, not human needs. A shift in thinking embracing neo-liberal ideas accompanies these institutional changes. Citizens are viewed as autonomous individuals responsible for their own actions and fate. Economic opportunity is recast as individual responsibility, not connected to social-structural conditions.

Under these conditions individuals are responsible for their own successes as well as their failures, leading to the importance of understanding the analysis of a risk society. A number of provisions have arisen to deal with managing risk (Rose, 2000), most beyond the confines of the state and state institutions (rendering an analysis of state institutions not irrelevant but only a small piece in a large puzzle). The power of the state is decentered (Garland, 1997) with diverse risk management strategies, under “a black hole” of new market conditions controlling identities (Bauman, 1997).

The promise of Marxism and political economy can therefore be assessed under this new terrain of risk management and governmentality (Pavlich, 2000). The grammar of authoritative judgement is not capable of challenging fragmented governmentalized risk-based, diverse political technologies. Attention must be paid to the changing epistemological horizon where judgemental grammar no longer can thrive (Bauman, 1997; Lyotard, 1984) and to recover a critique that does not serve the technocratic demands of

advanced neo-liberal and conservative governmentalities dominant today (Rose, 1996). Further, with the diversity acknowledged within literature on governmentality, the fractured social identities of postmodern conditions and life choices (in class, race, gender, age, sexual orientation) render the meta-narrative towards emancipation impossible. Can we realistically say there is a universal vision that is broad enough to address all of the oppressions of our time? Yet this is often what political economy approaches assume (Butler, 1992). Derrida points out that “nothing seems to be less-outdated than the classical emancipatory idea” (1992: 28).

Although the political economy theory captures class and racial inequalities and consider capitalist interests within the medical industrial complex, it continues to focus on a critique of centralized power. Foucault’s later work (1991) related to governmentality argues that state power has shifted from centralized control to a more decentered society and state (Garland, 1997; Rose, 1996; 2000).

2.3 Foucault and Governmentality

Foucault’s later work (1991) and governmentality theorists deepen the political economy analysis with their understanding that state power has shifted from centralized control to a more decentered society and state (Garland, 1997; Rose, 1996; 2000). We are living during a time of incredible diversity in identity and community. Governance forms a sub-politics and is done at a distance in multiple ways (Rose, 2000). The sub-politics formed (from the state, through new actors such as NGO’s, through to the responsabilization of citizens—including for health) means that the new forms of governance is an extension of control (Rose, 1996; 2000). Even the responsabilization of the new “moral and responsible citizen” is linked to economic responsibility (Eisler, 2008).

The governmentality perspective addresses current trends in governing strategies in Canada. For example, in the current economy, the government no longer seems willing to ensure full employment and social well-being. We have witnessed a downsizing of the public sector and slashing of both social spending and corporate taxes. Paul Martin and Stephen Harper have continued to dismantle the social democratic state in Canada. Dobbin (2003) argues that Paul Martin redefined the role of government in the lives of Canadians, especially in terms of social spending and lowering the deficit. Martin's reduced spending created a surplus, which meant larger tax breaks than ever before in Canada. Most of the benefits were received by corporations and the richest "8 percent of the population" (Dobbin, 2003: 4). Stephen Harper has also given enormous tax cuts, totalling fifty six billion dollars, called welfare for elites (Masuda, 2009). There was also a recent one billion dollar spending cut to social programs and services announced in September, 2006 (CUPE, 2009).

The 2009 federal budget and the Harper government is now claiming that deficit spending is required to boost the economy in times of a major economic recession. This stimulus package, however, does not provide strategies for the poorest Canadians and Harper seems ideologically committed to continue laissez fair economic strategies (Munn-Venn, 2009). According to Canadian Centre for Policy Alternatives, "only 5 percent of the budget is actually devoted to tax measures to help vulnerable low income Canadians" (cited in Munn-Venn, 2009). The poorest Canadians will be the most "hit" by the current recession and the first to lose their prospects for income—more Canadians will slide into poverty (Munn-Venn, 2009).

The UN has noted that drops in welfare benefits, inaccessibility of the employment insurance programs, insufficient minimum wage, evidence of homelessness and inadequate housing “amount to a national emergency” for Canada’s poor (UN Committee on Economic, Social and Cultural Rights; cited in *Toronto Star*, 2006). Increasing Canadians are living in poverty and class inequalities are growing.

These institutional changes and the “free market ideologies” are accompanied by a shift in thinking towards neo-liberal ideas (Clarke, 2000). Community members and citizens are viewed as autonomous and responsible individuals. Economic opportunity is viewed as an individual responsibility, even at times of economic crisis. This reinforces continued cutbacks in welfare provisions and further polarizes rich and poor, to which the state must respond (White, 2008).

Foucault writes about neo-liberalism (defined as a new “politics of truth”) as not simply as an ideological shift, but a change in relations of governing. Economic opportunity is no longer linked to social structural conditions, but is seen as linked to individual responsibility. Individual citizen’s failures and our successes are defined by the “freedom” to achieve them. Moreover, at a time of growing inequalities, there is a downsizing of the social safety net and a growth of penal industries. This extended governing is popularly coined “conducting conduct” (to conduct the conduct). Although there are multiple roles of governance, Nikolas Rose (1996; 2000) argues that we can define two major forms of control: circuits of inclusion and exclusion. Inclusion means citizens are responsabilized to care for their own destiny, their own security, their own health, their families’ well-being and their communities’ well-being. The notion of inclusion introduced managing risk. Social problems and social risks become the

responsibility of the individuals, communities, companies, etc. Unemployment, ill health, are not problems of socio-economics, linked to colonization, globalization, patriarchy, but are also the responsibility of subjectified and responsabilized individuals.

Ulrich Beck's (1992; 1999) argues that we are living at a time of increased risk which we are seeking to manage through responsabilization. Health is becoming a commodity that we are buying. There is a movement from the passive patient or consumer of health care, to the active consumer. Citizens become responsabilized to prevent illness, read health literature, consult experts including, for example nutritionalists—diversified and disembedded experts who are constantly changing opinion. The active consumer is self-reliant and self-determining as opposed to “the passive patient”. Citizens who used to have a right to expect services now have duties to protect themselves and reduce health risks. Only some people, however, have the material advantage to be able to manage risks. Further social exclusion results in deeper fears and an Othering of those we are excluding.

The self-esteem movement in the health literature is also telling. The self-esteem movement is connected to neo-liberal governance “at a distance” through responsabilizing individuals to see political problems as not rooted to “revolutionary solutions” but through a more “proper, responsible” governing of self (Cruikshank, 1999). In the governmentality literature it is also stressed that those who do not follow the “self-governing”, predetermined paths, are seen as “irresponsible.” Extended governance thereby includes ways of attaching these individuals. Other examples are educational options, job training, exercise programs, health groups and more. “The self-esteem movement is not limited to the personal domain, as its goal is a new politics and a new social order...it promises to solve social problems by heralding a revolution—not against capitalism, racism, patriarchy,

etc., but against the (wrong) way of governing ourselves” (Cruikshank, 1999; cited in Lemke, 2000: 13).

The governmentality perspective also introduces the concept of the stakeholder society. Citizens become stakeholders who must contribute towards the welfare of society and themselves: “Care of the self has become equated with “self-reliance,” with “freedom” from “welfare dependency,” and with earning the support and protection that was previously seen as an obligation of the state” (Petersen, 2003: 194). Upon implementation this means denial of benefits and services previously recognized as individual rights.

Petersen (2003) argues that the idea of the conduct of conduct should be complemented with how subjects transform and manipulate their own social context: “It is important that scholars acknowledge how particular strategies of rule create new avenues for action and new claims to citizenship rights based upon concepts such as “consumer,” “empowerment” and “participation” (2003: 198). Citizens have used their new consumer identities as a means for demanding better and more particular services. These are often based on identity categories such as indigenous people, race and disability.

Governmentality research may question how subjects collectively and individually deploy these practices and projects, yet within the context of governing strategies and power structures.

In this same way, we are living at a time whereby political dissent, addressing “isms” is criticized; “..in the age of intimate citizenship (Berlant, 1997; cited in King, 2003), in which politics via mass anger and disruption is dismissed as silly, futile, and even dangerous, an ethic of self-government has emerged that asks people to turn their critical selves inward, to question and work upon their psychic health and their self-esteem” (King,

2003: 306). A new type of citizen is defined by neo-liberal responsabilization, whereby challenges to the status quo are less tolerated and a new form of social activism is defined—one where we assist others to be responsible, healthy and successful. This volunteerism is defined by the needs of the global economy and fails to challenge status quo.

For instance, breast cancer philanthropy is defined by bourgeois values, led by high-profile corporate sponsors and fundraising initiatives are towards bio-medical and technical research and cures (King, 2006). This critique extends to the breast cancer fundraising runs: “In addition to the nation’s largest series of 5k runs, the Susan G. Komen Breast Cancer Foundation’s Race for the Cure, the dizzying array of challenges created by foundations and corporations include the American Cancer Society’s Make Strides against Breast Cancer, a non-competitive walk; the Danskin Women’s Triathlon, which raises money for the Breast Cancer Research Foundation; the Revlon Run/walk for Women...the Avon Walk for Breast Cancer...” (King, 2006: 29-30). The point is that these runs are established and shaped by corporate sponsors and the implication is a corporatization of breast cancer activism and consumption-based expression.

Even empowered approaches to research, such as photovoice exist within the context of neo-liberal citizenship and a modern dictate of responsabilized action, which presently demonizes political dissent. Paradoxically, this means that these movements and institutions (including this research) may lead to a reinforcing of the status quo and more ill health. This level of analysis is addressed in the Chapter 8.

2.3.1 Governmentality and Social Justice

Social justice from the governmentality perspective addresses de-centered power relationships. Power is everywhere and has shifted even to the “responsibilized” individual.

Governmentality is often talked about in relation to neo-liberalism, not simply as an ideological shift but as a change in the relations of governing. Governing now has new actors—from NGO's, self help organizations to responsabilized individuals. Individuals are now responsabilized for their own well being—and to manage their own risks. This means that unemployment, poverty and other social problems become the concern of the responsabilized individual. This type of social control is very powerful. It appears that we are responsible for our own destiny, yet, economic rationality and moral goodness/badness and ways of living our lives continue to be dictated.

The governmentality literature therefore allows questions about diversified individuals, de-centered social relations and social control. We begin to understand power as being everywhere, and can ask questions about different levels of social relationships, including the research relationship. The definition of social justice from this governmentality perspective includes an unravelling of these complex relations of social control.

2.4 Synthesis

Critical theories contribute to our understanding of social determinants of health and the social control of medicine. There is an abundance of literature on social determinants and environmental factors related to health and the importance of social class, production process, racism, economic cycles, material and social conditions and how these contribute to illness and mortality. Sociology of health and medicine has contributed an understanding of health, illness, inequalities and the social control of medicine. First, political economy helps us discover dominant injustice and links knowledge to material, historical and social contexts. From this perspective, injustice is rooted in unequal social arrangements—health/illness and medicine is a case in point. Second, governmentality theories extend the analysis of state power to decentered power and multiple sites, including responsabilized citizens. As such, my position is that these perspectives are complementary—we can recognize decentered forms of power modeled in governmentality without denying institutional, structured patterns of control modeled in political economy. From the governmentality work then, we seek to discover how our present is shaped beyond institutions, structures and patterns.

The political economy and governmentality perspectives provide a lens to understand the role of government in relation to health care in late modern society, especially the shift from welfarism to neo-liberalism and the impact on health care and models of citizenship. These theories deepen links to social justice and lines of questioning in the *Visualizing Breast Cancer* research about injustice, privilege, citizenship, collective

rights and social/economic, cultural/ideological and racial determinants of health. Medical dominance and preventative health strategies are located in the medical-industrial complex.

In summary, I first identify parallels between the women's stories and literature on the social determinants of health. I second apply the critical theories as a lens to understand the link between the VBC stories and deepened contextual understandings of social justice. Finally, although the critical theories of the political economy and governmentality help to contextualize the women's lives, the question of the women's agency and her own power and resistance is often left unaddressed. The critical theories provide a lens to question the context of the women's lives and the multiple layers and sites of oppression. However, an anti-oppressive framework, grounded in a combination of Marxism, feminism, postmodernism, anti-racism and postcolonialism, adds to this an understanding of diversity between the women and their multiple sites of power and resistance.

Governmentality and political economy perspectives are criticized for failing to recognize the importance of resistance and agency (Garland, 1997). In the governmentality literature, actors are responsible for creating their own subjectivity; however, this is always under constrained regulated choice. Society therefore remains the key object of analysis—witnessed in a range of rationalities and techniques that govern and regulate choices. Although human actors have the right to choose and are expected to do so, they do not have a right not to choose, and choice is only amongst predetermined options—“official goals.” The criticism of governmentality studies is that they fail to recognize difference and diversity within people's realities and privilege official definitions and discourse. Governmentality theorists are criticized for not researching resistance or counter discourses leaving a continued de-centered top down notion of what government is (Garland, 1997).

Political economists recognizes agency only amongst collectivities representing interest groups, race, classes and/or ethnicities. From this perspective, collectivities tend to be seen as singular, representing singularized political interests and action—criticized for essentialism. I argue that governmentality and political economy both call for a more in-depth understanding of agency—developed by anti-oppressive and feminist frameworks—the topic of the next chapter.

Chapter 3 “The women’s movement must come to terms with Aboriginal women’s diversity *as we define it*”⁴: Feminist, Anti-Oppressive, Anti-racist and Postcolonial Theories

In Chapter 2, I concluded that combining social epidemiology with the critical theories of governmentality and political economy is important. In this chapter, I suggest that these theories can be combined with anti-oppressive theories, such as postcolonial feminism, which together provides an appropriate lens to understand Aboriginal breast cancer survivors’ experiences. These combined approaches demonstrate that Aboriginal women’s breast cancer experiences and photovoice methodologies are best understood through an acknowledgment of the links to complex structural and governing processes, while carefully understanding the intersectionality of oppression and agency. Towards a rationale for combining these critical theories with feminist and anti-oppressive paradigms, this chapter provides an overview of both feminist and anti-oppressive theories, introducing the importance of gender, agency and voice.

Feminist and anti-oppressive theories identify the importance of including women’s voices while recognizing that women’s agency is shaped by but also shapes larger relations of power and social control. These feminist-based theories engage the question between human agency and social structure—essential to understanding the different meaning of “empowering” Aboriginal women survivors of breast cancer and the impact their stories will have on the social forces that affect their lives. While feminist and anti-oppressive theorists agree on the importance of identifying the women’s voices, they differ in their analysis the relationship of women’s agency and discursive and structural relations. Some

⁴ Monture-Angus. 1995: 178

feminist theories give primacy to certain social structures, such as patriarchy. Other feminist theories give primacy to agency, while acknowledging the intersection of patriarchy, capitalism and colonialism. The literature I draw on for this chapter is particularly helpful in understanding ways that feminist and anti-oppressive perspectives engage women's voices and pictures.

“New” theories often arise through dialogues with existing ones. Rather than focussing solely on anti-oppressive theories, I therefore move through their dialogue with other forms of feminism, identity and critical theories. I introduce first prominent feminist debates on agency, voice and justice and the dialogue between 1) first and second wave feminism; 2) postmodern feminism; and 3) standpoint feminism. Secondly, I expand on the more recent difference-centered and anti-oppressive and feminist models. This section includes a discussion on anti-oppressive theory including: 1) anti-racist and critical race feminism; and 2) postcolonial indigenous theory and postcolonial feminism. The political economy and governmentality theories add to the contextual analysis of social power and the potential that empowerment research such as photovoice has towards social justice and social transformation.

3.1 Feminist Theory

3.1.1 First and Second Wave Feminism

Feminists, like Marxists and other critical theorists, clearly intend their theorizations to serve emancipatory ends...using theory as another site of struggle for the liberation of women from gendered oppression (Lather, 1991; cited in Moosa-Mitha, 2005).

First and second wave feminists focus on including experiential knowledge and the voices of women in theory (Moosa-Mitha, 2005). Common throughout first and second wave feminism is a critique of ideological, societal and institutional oppressions, gendered

assumptions and patriarchal conventions (Dominelli, 2002). First and second wave feminism, however, have been criticized for privileging gender over racialization or class and for focussing on problems related to relatively privileged women—most often white, middle class heterosexual women. My analysis incorporates first and second wave feminist viewpoints on the importance of including women’s voices and provides additional critique of these theories for essentializing “women” and “patriarchy”—assuming universalistic categories.

First and second wave feminist theory has a vision of justice for women against patriarchy and unjust gendered relations—and incorporates liberal, radical, Marxist and socialist feminism. Liberal feminists fail to challenge the status quo, but recognize women’s unequal position and aim to increase women’s status through liberal ideas of equality and inclusion of women within male-oriented liberal social justice visions (Timpson, 2001). Marxist feminists focus on capitalism and unequal class positions, demonstrating women’s unequal position within labour and the value of their traditional reproductive labour (Luxton, 2006), but fail to address issues of race, sexuality or other forms of oppression. “It is women’s economic dependence on men within the capitalist system that leads to their exploitation and inequality...the division of labour according to sex, a key feature of capitalism, [is] central to women’s oppression” (Calixte, Johnson and Motopanyane, 2004: 14).

Radical feminists argue that patriarchy existed prior to capitalism and argue, contrary to Marxist feminists, that patriarchal relations and male supremacy results in widespread repression (Eisenstein, 1979). Radical feminists define oppression as “based on

the relations of domination and subordination between the sexes, where women are seen as a sex class, whose sexuality is directly controlled by men” (Calixte et al., 2004: 20).

Socialist feminists have realized a dual-system model, which allows analysis of reproduction and production as spheres that are interrelated within society. Their focus on class and patriarchal gendered relations provides attention to both women’s exploitation within labour as well as well as realization of men’s control over women (Comack, 1996).

More recent difference-centered feminist theories (sometimes identified as third wave) have contested the critique of gender as a universalistic concept (Hill Collins, 2000). Feminist discourse theories, such as postmodernist and standpoint, argue that there is no “ultimate truth” rather that truth is partial, political and constructed. Some argue that “truth is a story” that there are a multitude of truths (Comack, 1996; Wonders, 1999). These perspectives provides a critique of first and second wave feminist theories (and of functionalist, Marxist and other earlier sociological theories) for attempting to provide universalistic explanations able to speak for all women—and assuming women will experience health inequalities in the same way. Donna Greschner (1994: 110; cited in Comack, 1996: 34) says: “those who say they can speak for others show a profound disrespect for them.”

Postmodernist and standpoint feminists challenge the standard feminist effort to establish a standpoint that represents all women’s voices (Kourany, Sterba, and Tong, 1999). Such a synthesis is not desirable or feasible because of the diverse experiences of women across class, racial and cultural lines, and also because a universal truth is a philosophical myth which demands submission of alternative truths (Kourany et al., 1999). Smart (1995), for example, attests that the unity surrounding feminist inquiry is and has

been limited by colour and class blindness and the belief that change can be sought through the welfare state and breast cancer research. Other feminists (see, for example, Hawkesworth, 1989), argue that this postmodern view, and the uncertainty it causes, is a conspiracy to undo years of feminist struggles and utopian visions (cited in Smart, 1995). Cain (1990) and Harding (1991) assert that postmodernism makes feminist politics obsolete because of its apolitical nature. Here, I demonstrate the value of postmodern feminism for renouncing meta-narratives, offering deconstruction, revealing hierarchical text and multiple forms of governance (as well as identity), yet I criticize postmodern feminism for simplifying feminist epistemology and the feminist quest for emancipation. I then introduce a standpoint position, which credits the postmodern feminist position for recognizing truth as a philosophical myth, yet keeps the door open for numerous and constantly shifting feminist politics.

Within the VBC research, the postmodern feminist perspective enhances my understanding of how women's way of knowing is both shaped by discursive relations (such as binary constructions of race and gender) and why their way of knowing has remained hidden in favour of more mainstream medical constructions/discourse on "Aboriginal health and healing." The latter may include, for example, bio-genetics research, which has been used to biologically justify constructed categories of "race." Each of the following theories and the final analysis of the VBC work adapt the postmodern critique of discourse and discursive power. In addition, standpoint feminists offer the VBC research new insights into the importance of voice and understanding the multiplicity of truths/perspectives. Standpoint feminists accept the postmodern idea of multiple truths, but realize the impact of both structure and discourse, ideologies and governance at a distance.

This standpoint position provides reinforcement for beginning from the standpoint of the breast cancer survivors and recognition that the women's stories must be understood in the social context of their lives—including how each woman may experience these social forces differently. Standpoint and postmodern feminist perspectives introduce the limitations of establishing constructed “truths”, essential to understanding our postcolonial anti-oppressive framework and the limitations of critical work which attempts to ascertain an epistemological “truth” of experience.

3.1.2 Postmodern Feminism: “Truth is Like a Story”

...postmodern feminism [is linked] closely to deconstruction, characterizing this as a process that is universally and radically critical, anti-essentialist, and fiercely committed to breaking down traditional antinomies such as reason/emotion, beautiful/ugly, self/other, and the conventional boundaries between established disciplines. (Crotty, 1998:168).

Postmodernism is a critique of modernism—the search for truth (grand narratives) through science (Comack, 1999a; Wonders, 1999). Postmodern feminists argue that there are many competing truths—all contingent on personal judgments and understandings, which are historically specific and temporary. All truth is political, partial and subject to change. The social construction of “truth”, which are social constructions or interpretations of events in the world, is done via language and text, and each individual will read this text differently.

Whereas many social theorists focus on institutions and hierarchies where one group exercises power over another, postmodern feminists view power “everywhere”. Postmodern feminists challenge this way of viewing power by attesting to power residing in everyday interactions including behaviours, cultural symbols, ideas, material objects, language and nonverbal behaviour (Wonders, 1999). The construction of “difference”, for

example, is viewed as a mechanism of power. Difference is socially constructed through dichotomies where one part is held as better—what begins, as a continuum, becomes a dichotomy. Skin color, for example, is a continuum that assumes categories of “race” where whiteness is privileged. Differences are constructed linguistically and the relationship between the halves is ignored in favour of a binary construction that is elevated as natural. Gender is also investigated as part of identity politics (Kourany, Sterba and Tong, 1999; West and Zimmerman, 1987; West and Fernstermaker, 1995) where “maleness” has been privileged. Gender is not a biological fact but is an accomplishment within social interactions changing historically and across cultures—from deciding what to wear, how to talk, how to behave (West and Fernstermaker, 1995). Gender identity results from a set of relationships tied to historical meaning. For example, legal discourse constructs “woman” and “man” in contradistinction to each other and amongst themselves. Women are identified through both the law and medicine as pathological, “the female criminal, the prostitute, the unmarried mother, the infanticidal mother” (Smart, 1992; cited in Comack, 1999b: 65), constructing identities and changing lives.

Minow (1990) explains that classification and identification consequently positions people in relation to these created meanings. Classifying something as “unlike” the others uses language to divide the world and to discriminate. Postmodern feminists argue that the scientific method is not objective but, as any methodology does, relies on the subjectivity of the individual who is investigating. Postmodern feminism thus, has as its subject, (the historically specific) discursively constructed subject (Smart, 1995; Comack, 1999a). Postmodern feminist authors, such as Butler (1993) explain identity politics using the term “positionality”, which is the process whereby meaning becomes attributed to things, which

then assume those meanings (similar to self-fulfilling prophecy) (Butler; 1993; cited in Wonders, 1999:118). The language that defines meaning becomes associated with the person or group to whom it is applied. This discursive practice associates language and symbols to certain individuals and/or groups. Butler (1993) assumes that discourse produces effects so named through a process of reiterative and citational practice.

Deconstruction, for postmodern feminists is central to both a critique of discursively constructed subjects and social reality (Smart, 1995) and to opening up possibilities for social change (Wonders, 1999). The deconstruction of socially constructed language, symbols, texts and signs demystifies and reveals the hierarchical presuppositions imbedded within them. This deconstructive analysis opens space for new interpretations of events and text (Smart, 1995; Wonders, 1999). The task for the postmodern feminist is not to ascertain “truth” but to study the process through which socially constructed meaning and “truth” come into being (Smart, 1999). For example, rather than studying and assessing health decisions, postmodern feminists research how illness and health are constructed—how officials interact and give meaning to health, how decisions are made by subjective actors and how these become interpreted.

Definitions of “justice” from a postmodern point of view are difficult to create. Universal justice, from this perspective, is impossible (Wonders, 1999). Many postmodern feminists resolve this by recognizing justice as related to time, person and place (Elam, 1994), where it becomes everyone’s responsibility to make the best possible decisions in every moment. Because we are continually shaping the reality of the world we have a greater responsibility to construct it in ways that we can feel good about. Writers such as Elam (1994), for example, describe the “ethical activism” of postmodernism—the

responsibility or obligation that we must undertake when we recognize our role in daily creating reality and justice. Ordinary people as well as justice officials create social justice, which implies that we must take responsibility for the ways our decisions are helpful or hurtful—appreciating the ways in which language is political and can constrain individuals from full human potential (Elam, 1993; Wonders, 1999).

Smart's critique of knowledge as a form of prediction leads to a postmodern feminist critique of the deployment of politics in a postmodern habitat. This furthers the critique of modernist concepts such as society, system, class, race or gender, which are considered more appropriate to capture an ordered universe where a (welfare) state can be identified as a means towards addressing disorder and oppression. Postmodern society is characterized by numerous agencies, each with a different agenda—"none of which is powerful enough to override the others" (Bauman, 1991; cited in Smart, 1995: 212). We are living in a time where there are multiple identities, incredible cultural and community diversity. The role of the state is changing from one of providing for the health and well being of a community towards acting as the "animator and facilitator" for a diversity of practices and agencies. Analysis of social control therefore must be directed towards the school, street, hospital, clinics, prisons as well as academic and feminist research—all far from the welfare state.

A number of appealing themes can be summarized from this brief overview of postmodern feminism—and (as we will see) are adopted by anti-oppressive frameworks. First, a key insight is their definition of the only "pure" philosophical quest as that which uncovers how meaning and truth arise, as well as the changing and political nature of discourse. Second, postmodern feminism is also appealing for its ability to deconstruct the

power held in medicine and other institutions as well as text, language and any context of meaning, alerting the ideological representations of gender, race and class (without succumbing to pre-given categories of what these constitute). The identification of the changing nature of the state, the rising of numerous agencies, multiple identities and governance at a distance adds important insight into the diverse workings of power. This also provides a critique of modernist feminist knowledge which seeks emancipation through the welfare state. The idea of ‘diverse workings of power’, ‘positionality’ and the ‘discursively constructed subject’ I argue, is similar to ‘culturalism’ as defined by anti-oppressive frameworks and, as we shall see in Chapter 7, adds to the understanding/warning of how Aboriginal women’s culture and worst case scenarios (of, for example, poverty and violence) are discursively constructed and have become associated with an entire ‘race’, reinforcing discriminatory exploitative practices in health care and beyond. This type of analysis provides essential warnings to how the visual images and stories of the survivors are interpreted.

The appeal of postmodern feminism notwithstanding, postmodern feminism is also criticized on at least three grounds: for claiming “knowledge” unavailable or somehow unacknowledged by other theoreticians; for giving epistemological primacy to discourse, thereby negating the power of social structures; and for separating feminism from emancipatory politics. It seems postmodern feminism dances the academic three step (Stanley and Wise, 1990; cited in Comack, 1999a) too freely, and could acclaim or adopt rather than refute work of other feminists. Other second and third wave feminists (including socialist feminists and standpoint feminists) also identify socially constructed hegemonic ideologies of masculinity and femininity, criticize the reification of binary

constructions and identify their roots and construction within gendered institutions. They also identify the makeup and subjectivities of decision makers within power positions (Mandell, 2001). Similarly, the idea of the postmodern state—numerous agencies, multiple identities, and changing nature of governance—is adopted by many feminists and governmentality theorists who acknowledge multiple realms of hegemonic power (Comack, 1999a).

My final critique of postmodern feminism concerns the position that epistemology cannot lead to emancipatory politics. This claim calls into question the marriage of postmodernism and feminism, simplifying the quest for emancipation and feminist epistemology. I argue that these de-centered forms of social control can be examined with the spirit of a critique which acknowledges human potential lost and that postmodern feminism does not contradict the Marxist emphasis on change and escaping present life limits. Postmodern critiques can embrace the spirit of Marxism and concepts of justice and democracy as promises that are ongoing—not specific endpoints that are achievable. This, I believe, is the agenda of standpoint feminists and anti-oppressive theorists. There cannot be an emancipatory goal, but we may embrace ongoing critique.

3.1.3 Standpoint Feminism

Standpoint feminism, like postmodernist feminism is a powerful critique of the ways in which fractured social identities of postmodern conditions and life choices (in terms of class, race, gender, age, sexual orientations) render meta-narratives towards emancipation impossible and outdated. The method of deconstruction, revealing internal hierarchies in all levels of governance, including feminist politics, is a meaningful challenge to modernist research, also evident in standpoint feminists writing (Comack, 1996). Yet, while standpoint feminists may embrace the postmodern feminist agenda of deconstructing all truth-claims as potential forms of governance and social control they do not negate the power of social structures. Nor do they neglect the feminist responsibility towards a politics which may consciously and reflectively recognize emancipatory goals (Comack, 1999a). Standpoint feminists such as Comack (1999a) attest that feminism does not aim for absolute universal truths, but to produce representations of the truth that are less perverse or partial:

It must be emphasized that my knowing (as with all forms of knowledge) is partial. It is partial in the sense that it is each woman's perspective that I am listening to; her telling of her life. It is partial in that what gets told depends very much on what a woman was willing or able to disclose to me at the time. As one woman commented: "I haven't told you everything" (Even so, what she did tell me was probably all I could handle at the time!). It is partial in that what I was told is also dependent upon the kinds of questions I posed, the sort of information about a woman's life I chose to elicit from her (Comack, 1996: 13)

Standpoint feminists argues that a more complete understanding of women's lives are offered if we combine the experiential subject of standpointism and the discursively constructed subject of postmodernism (Comack, 1999a). This means acknowledging that women's experiences are affected by non-discursive relations as well as discursive.

Postmodern feminists give ontological primacy to discourse, denying the extra non-discursive realities, which lie outside of discourse and affect women's lives (Comack, 1999a). Standpoint feminists define this as the fallacy of "epistemological primacy" and articulate the importance of giving ontology to social relations, which are powerful and exist in autonomy of knowledge (Cain, 1990).

Women's knowledge of their lives is necessarily partial because it is shaped by their histories, culture and social context. An implication of postmodern feminism seems to be to abandon the reality of structures such as imperialism, capitalism and patriarchy. Comack (1999a) argues that it would be naïve to acknowledge that social categories such as race, gender, and class exist as perpetually changing discursive constructions (as postmodernists do), yet deny the reality of the impact these socially constructed realities have on people's lives. Comack (1999) argues that feminist research can study how the dynamics of class, race and gender are worked out in the everyday lives of women without, she argues, imposing these categories on the women, and while acknowledging that these are socially constructed.

Comack (1999b; 1996), argues that the acknowledgement of these structures does not negate the importance of everyday social interactions or social agency, but rather suggests that choices may be shaped and influenced because of individuals social positioning within institutional structures.

Standpoint feminists then provide new insight into the importance of voice—and understanding the multiplicity of truths/perspectives. Accepting the nature of multiple truths, realizing impact of both structure and discourse, ideologies and governance at a distance, standpoint theorists begin from the work as it is experienced by women. Dorothy

Smith (2005) argues that we must begin with the standpoint of people and that no two people can have the same standpoint. Smith (2005) emphasizes that we begin with what we know of the world, but that this is conditional upon one's social location. We have a given standpoint depending on our social location which means that one cannot have complete objective knowledge. Comack (1996; 1999) concurs, demonstrated through her research with women in trouble:

In taking the women's lives as my starting point, my aim has been to develop a way of knowing...that is capable of shedding light on the factors and conditions which brought them into conflict with the law. Central to the formulation of this standpoint is the attempt to situate their lives within the nexus of the class, race and gender relations of our society (Comack, 1996: 34).

While agency has to be accounted for, standpoint theorists also insist social structures—patriarchy, colonialism, capitalism and imperialism, condition individuals' choices: "While we need to acknowledge that individuals possess power and make choices, social power is unevenly distributed along a number of different axes—most notably, of class, gender and race" (Comack, 1996: 31). "Reflexivity" means academics are also called upon to identify their own standpoint, including how this interacts with their research.

In sum, standpoint feminists link Marxist concerns of domination and structure with a phenomenological emphasis on active construction of consciousness and social reality. This results in standpoint feminists call "a faithful telling" of the social world, which arises in the actual experience of subjects. But the experience of the subjects are also linked to larger institutional imperatives and macro structures (Smith, 2005). This standpoint position draws attention to the discursively constructed subject and the experiential subject, while acknowledging how women's choices were affected by (and affect) patriarchy, colonialism and capitalism (Comack, 1996). Ontological primacy is

given to the standpoint of the participant and multitude of truths and lived experiences are acknowledged. Only then are commonalities between women's experiences and shared common experiences recognized.

For the VBC research, what standpoint feminism offers, different from postmodern feminism, is that lived experiential knowledge of the women can be developed into a women's standpoint. This standpoint can then be used towards the development of policy which may enhance theirs and others' lives. This standpoint is recognized to be affected by colonialism, capitalism and patriarchy—class, race and gender—and the ways that women experience/cope within these structural confines is understood as diverse. While acknowledging discursively constructed “truths” and heterogeneity, the standpoint developed must be understood ‘reflexively’. Research and analysis was done at a particular time and place and the research was framed in a way which reflects the context of the women and the researchers. The “rules” of standpointism insists that while this research and resulting policy may be relevant for these women at this time and place, this cannot be generalized to all Aboriginal women with breast cancer, and that the research conclusions must make this clear.

The critiques of feminism and introduction of postmodernism and standpoint feminism have created space for a difference-centered analysis which include anti-racist, critical-race feminism, postcolonial and anti-oppressive theorists who recognize oppression arising from within multiple sites—gender, class and racial sites of oppression and introduced the concept of “intersectionality.” The reflexivity of researchers introduced within standpoint feminism, also carries through to anti-oppressive theories.

3.2 Anti-Oppression and Identity Theories

Originally, anti oppressive theories (in their origin in the 1990s) brought in the notion of intersectionality of oppressions (Razack, 1998; Hill Collins, 1998). Authors such as hooks (1989; 1990), and Hill Collins (1998) argued that we cannot single out, for example, racial oppression but that oppressions are interrelated. Anti-oppressive theory saw the elimination of all oppressions as part of their emancipatory aims. While adapting the strengths of postmodern deconstruction and standpoint's experiential subject, this work provides a key lens for seeing intersecting social forces which affect Aboriginal women's experience of breast cancer.

Similar to postmodern and standpoint feminism, this perspective argues against the universalism of enlightenment based thinking. Following the assumptions of postmodernism, anti-oppressive theories appreciate that there is no essential truth to experience. Thus we cannot essentialize identities within any categories—of class, race, gender or ethnicity. This also means an appreciation of the fluidity of these categories and a critique of binaries (of race, gender, sexuality, etc) which create 'difference'. Identity is acknowledged as fluid and changing, not essential. Identity is relational to discursive construction. There is recognition of difference, while acknowledging the dialectical relationships with relational, cultural and structural factions. We therefore must also deconstruct the dichotomy of oppressed and oppressor and recognize that people can speak from both locations simultaneously and that there is power found within the margins (Razack, 1998).

Anti-oppressive theories recognize the importance of agency and subjectivity. It is essential to begin with the standpoint of the oppressed and hear the voices that have traditionally been lost (especially within enlightenment thinking which spoke for the Other). Anti-oppressive theories recognize difference between people's experiences and similarities in the experience of the communities. Patricia Hill Collins (1998), for example, aims to bring forward the voices and experiences of African American women, with an understanding of the intersectionality of oppressions, recognizing differences of experiences and similarities in collective experiences of communities: "For example, the heavy concentration of U.S. Black women in domestic work coupled with racial segregation in housing and schools meant that U.S. Black women had common organizational networks that enabled them to share experiences and construct a collective body of wisdom." (Hill Collins, 2007: 347-348). This means, for example, that African American women, and by extension, Aboriginal women, in the Saskatchewan and Canadian context share certain experiences with discrimination regarding housing, employment and more. They also share situated experiences such as being watched or discriminated in everyday living situations.

Anti-oppressive theories add to their analysis the idea of subjugated knowledges. People who speak from the margins of society have "the privilege" of recognizing not only their experience, but the reality of the experience of those in positions of privilege (Moosa-Mitha, 2005). An Aboriginal woman has the knowledge not only of her cultural historical realities, experiences of everyday living, but also has the knowledge of the mainstream society.

Knowledge is both subjugated and situated, which means that while agency is important, it is situated within a multiplicity of oppressions and relationships (Hill Collins, 2000). It is not possible for someone who is not racialized to understand what the experience of being racialized in a community means (Moosa-Mitha, 2005). Because knowledge is subaltern, researchers are in the position of “not knowing” and must stay in a position of a learner asking for the privilege of learning. Knowledge in this way is also emancipatory. New knowledge is created that was not recognized before which brings with it a new appreciation of difference.

Anti-racism, critical race feminism, postcolonial indigenous and feminist theories represent anti-oppressive theories and give rise to more specific questions relevant for Aboriginal women’s health concerns—especially drawing attention to colonialism, neo-colonial realities, racialization, culturalism and the ways these intersect with gender, class and impact life chances and health.

3.2.1 Anti-racism and Critical Race Feminism

We will not reach new possibilities through a simplistic and binary freezing of difference and sameness, of women vis-à-vis men, and of “us” vis-à-vis minority and Third World communities. We need to learn to see and challenge the multiple, overlapping, and discrete oppressions that occur both within and across white/Western and Third World/non-white communities. Otherwise, we remain mired in the battle of feminism versus multiculturalism (Volpp, 2003: 402).

Anti-race theories and critical-race feminism understand an intersectionality of oppressions, the importance of difference, heterogeneity, subjectivity, situated tellings and multiple voices. Anti-racist research strategies focus directly on race (Okolie, 2005). Critical Race Feminism (CRF) focuses on re-entering the voices and experiences of women at the margins towards justice and the creating of justice strategies (Wing, 2003).

Beginning with an understanding of the very real impact of racism and the importance of hearing multiple voices, anti-racist researchers also aim to give back voice within experiential research (especially, some argue, through storytelling in racialized cultures whereby this has a long history (see, for example, Okolie, 2005). The difference between this work and standpoint feminist theory, is that this is to be done in a way which is holistic (including spirituality—not simply linear tellings) and which emphasizes emancipation and elimination of racism. Experiential accounts (multiple tellings) are important. The reality of racism demands, however, that these accounts must not stay just at the level of the individual. Racism is experienced individually, relationally, societally and politically. The aim of the anti-racist researcher is to ensure the experiential account includes the political and structural problems inherent within racism and social construction of race (Okolie, 2005).

Critical race feminists focus on the interaction of race and gender: “Because the intersectional experience is greater than the sum of racism and sexism, any analysis that does not take intersectionality into account cannot sufficiently address the particular manner to which black [racialized women (my emphasis)] are subjected” (Crenshaw, 2003: 24). CRF critique “gender essentialism”, that all women experience oppression the same. CRF also criticize “race essentialism”, that all racialized people experience oppression the same. Harris (2003: 34), for example, writes:

The effect of gender and racial essentialism (and all other essentialisms, for the list of categories could be infinite) is to reduce the lives of people who experience multiple forms of oppression to additional problems: “racism + sexism = straight black women’s experience,” or “racism + sexism + homophobia = black lesbian experiences.” Thus, in an essentialist word, black women’s experience will always be forcibly fragmented before being subjected to analysis, as those who are “only

interested in race” and those who are “only interested in gender” take their separate slices of our lives.

The position of both anti-racist and CRF is that placing marginalized peoples “at the centre” helps challenge complacency and assists in developing a counter-hegemony critical of dominant discourses, providing the basis for unifying political activity. Critical race theory and CRF address systemic and historical conditions associated with racism which are essential to contextualizing Aboriginal women’s experiences of breast cancer. Postcolonial indigenous theory and postcolonial feminism also acknowledge the intersectionality of oppression, address systemic and historical conditions related to racism, and have developed questions specifically regarding Aboriginal peoples and Aboriginal women in Canada.

3.2.2 Postcolonial Indigenous Theory and Postcolonial Feminism

Colonization has taken its toll on all Native peoples, but perhaps it has taken its greatest toll on women... (LaRocque, 1996: 11-12; cited in Browne, Smye and Varcoe, 2007: 128).

Postcolonial feminist theory stems from a dialogue with other forms of feminist theory, anti-racist theory and postcolonial indigenous theory. Key for postcolonial indigenous theory is a concern of colonialism, neo-colonialism and its continued impact on people’s lives (Reimer and Anderson, 2002). Neo-colonialism is less overt than colonialism, sustained by everyday assumptions, processes and structures, and refers to current control measures of indigenous peoples (Ashcroft, Griffiths and Tiffin, 1998).

Postcolonial feminism, like postcolonial indigenous theory and anti-racism has as their goal transformative social change. The challenge is to focus attention on heterogeneity and context particularities, while generalizing about shared experience especially related to marginalization through racialization and socio-economic oppression.

Postcolonial-feminists illuminate connections between gendered positioning with class and racialization while acknowledging colonial histories, neo-colonialism and the effects on current lives, choices and opportunities (Anderson, 2000; 2004):

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 (Browne, Smye and Varcoe, 2007: 128-129).

Postcolonial-feminist theorizing aims to address social determinants of health, including historical determinants found through colonialism and neo-colonialist relations. Health inequalities are found through a critical gaze, informed by an understanding of women's experiences, contextualized in the wider political, social, economic and historical context. The 1876 Indian Act, for example, meant forced assimilation of Aboriginal peoples through appropriating lands, outlawing spiritual and cultural practices, forced indoctrination into dominant culture through residential schools, forced marginalization onto reserves. 'Status' or 'Registered' First Nations continue to be governed under the Indian Act—and Aboriginal women are argued to have fewer “fundamental rights than men” (Fiske, 2006; cited in Browne, Smye and Varcoe, 2007: 131). Under the Indian act, and until the amendment of the controversial Bill C-31 (Monture Angus, 1995; Cannon 2007; 2008), Aboriginal women lost their status and rights/protection if they married non-Status Indian men or non-Indian men. This affected their ability to, for example, own property which has had an impact on their current rates of poverty and therefore poorer health (Dion Stout, Kipling and Stout, 2001). Although amended through Bill C-31, continued effects are felt (Monture-Angus, 1995; Cannon, 2007; 2008).

It is well known that Aboriginal women's socio-economic status is lower than non-Aboriginal peoples in Canada and that they suffer higher levels of poverty. Some scholars link colonized histories to levels of poverty and argue that this: "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" (Dion Stout, Kipling, and Stout, 2001; cited in Browne et al., 2007: 131). Monture-Angus (1995: 175) asserts that feminist movements have "never taken as its central and long-term goals, the eradication of the legal oppression that is specific to Aboriginal women...this is an example of where colonialism must be incorporated in feminist analysis". Many Aboriginal women have therefore constructed identities related to gender that are quite distinct from feminist movements and distinct from non-Aboriginal women (Browne, Smye and Varcoe, 2007).

Postcolonial-feminists agree that perspectives of marginalized peoples must be the starting point towards the development of knowledge and deconstructs the social construction of race, culture and Other. This perspective asks why Aboriginal women are more susceptible to certain "risk." Yet this perspective also warns that assumptions about class, cultural and racialized identities which inform medicine and mainstream theories of "risk", creates/reinforces difference, Othering and culturalism. The process of Othering means that stereotypical (and often racialized) assumptions of identity, culture and difference are placed onto certain groups which are not reflective of actual identities. Through the continued effects of colonizing and neo-colonial practices, Aboriginal women have often been identified as an "inferior" and "subordinate Other" (Anderson et al., 2003; cited in Browne et al., 2007). Additionally, theories which draw attention to specific racial

groups risk “culturalism”—reinforcing stereotypical assumptions and cultural essentialism. For example colonizing images of Aboriginal women is part of history and the present day. Cultural essentialism can result from well-intentioned efforts to attend to differences within cultures. Narayan (2000; cited in Brown et al., 2007), for example describes how many women from “Third World” cultures are essentialized based on the most underprivileged. Similarly, Canadian research glosses over heterogeneity, linking Aboriginal ‘culture’ with social problems related to poverty, dependency, addiction and poor health (Browne and Fiske, 2001; Browne, Smye and Varcoe, 2007):

Colonizing images of Aboriginal women as irresponsible and negligent contributed to the ‘inferiorization of Aboriginal motherhood,’ fuelling the widespread removal of Aboriginal children into non-Aboriginal foster homes in the 1960s and 70s (Fiske, 1993: 20).

The problem of culturalism and Othering is also true when interpreting health statistics and indicators. Profiles of health and statistics alert communities to important trends regarding health and illness. There are, however, important risks in reporting trends without contextualizing this within social, economical and historical determinants. The wider determinants of health evident in the intersecting of class, culture, racialization, historical subjugation and gender are easily overlooked in favour instead of blaming individuals and groups of people/cultures for lifestyles associated with ill-health:

...recognizing that the high rates of diabetes and obesity affecting many Aboriginal women are linked to overall changes in socio-economic status within entire communities, and associated diet and exercise patterns, avoids misinterpreting these conditions as purely 'lifestyle' issues arising from people's unwise choices. Similarly, substance use problems experienced by some Aboriginal peoples have been linked to intergenerational traumas associated with residential school experiences among other multi-factorial issues (Royal Commission on Aboriginal Peoples [RCAP], 1996) (cited in Browne, Smye and Varcoe, 2007:132).

The postcolonial-feminist literature introduces the concept of "cultural safety" as a lens which simultaneously views individuals in their location, related to colonial marginalization (Wood and Schwass, 1993). The idea of cultural safety is that researchers, policy makers and health care workers, ensure the effect of history, especially colonization is understood when addressing Aboriginal women's health concerns (Browne and Fiske, 2001). This does not mean simply being sensitive to cultural differences or specific needs, but acknowledging inequalities and the effects of colonization and neo-colonialism: "Cultural safety moves beyond notions of cultural sensitivity to an analysis of power imbalances, institutional discrimination, and the nature of the relationships between the colonized and colonizers as they apply to health care interactions at the macro and micro levels" (Browne and Fiske, 2000: 8-9).

In sum, postcolonial-feminist theory provides an understanding of how health and life chances are affected by the intersection of class, culture, racialization, historical subjugation and gender. This theory emphasizes critical and inclusive analysis, marginalized voices, especially those who have suffered effects of colonized histories. The concepts of culturalism, cultural safety, and the emphasis on the intersection of colonial history are key to my analysis of the Aboriginal women breast cancer survivors and this

present study. It is my position that the Aboriginal women's stories must be understood in the context of colonial histories using a lens of cultural safety.

3.3 Synthesis

Anti-oppressive theories are then congruent with the idea of first, second and third wave feminists and their focus on bringing back experiential knowledges of women. Anti-oppressive theory criticizes feminism for essentializing women and negating intersecting oppressions. The oppression of women (in this case often Caucasian women—and often privileged) seems to be assumed. This is important in the breast cancer literature, especially as the disease is presented in the media often as a “white” woman's disease.

Anti-oppressive theories also acknowledge the importance of recognizing class and materialist basis of oppression in the Marxist theories and recognize the importance of the emancipatory goals of these paradigms, yet criticize Marxism and political economy theories for assuming class oppression is experienced by everyone in the same way. Marxism is also (of course) criticized for failing to appreciate the intersectionality of race, gender, age, and ethnicity—and focusing instead simply on class.

The anti-oppressive theories acknowledge postmodern theories for their critique of “universal truth claims” (found in Feminism and Marxism). They appreciate the postmodern position that discourse becomes power and for their recognition of difference. Yet, they criticize postmodernists for failing to be emancipatory in their analysis and for not always being critical. Anti oppressive theories are identified through acknowledging difference, being critical and emancipatory goals of research (Moosa-Mitha, 2005).

Chapters 2 and 3 have reviewed many prominent Sociological, feminist and anti-oppressive theories relevant to the health literature. In the present study, I favour a combination of anti-oppressive feminist theories, (especially postcolonial feminism) and critical theories (especially political economy and governmentality). These combined approaches demonstrate that health/illness, Aboriginal women's experience of breast cancer and the potential of empowering methodologies like photovoice, are best understood through acknowledging their links to complex structural and governing processes, while carefully understanding the intersectionality of oppression and agency.

The feminist experiential approaches to breast cancer experience, which have been done (see, for example, Wilkinson, 2000; Thomas-MacLean, 2005), 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 (Lopez, 2005), I argue, rather than simply add "race", research must develop the importance of understanding interconnections of social contextual forces that affect women's lives. Colonization has resulted in a combination of oppression by race, gender and class, and analysis of breast cancer experience for Aboriginal women, therefore needs to be layered and complex.

The combination of critical and anti-oppressive paradigms provide a lens to understand how gender, racialization, class and historical positioning (especially considering colonialism and neo-colonial realities) shape women's voices, experience and communities. Together these theories inform questions about: historical and social determinants of health (critical and anti-oppressive theories); structures, institutions and processes of domination (political economy); situated voice (critical and anti-oppressive

theories); extended governing strategies, responsabilization, neo-liberalism and a new form of responsabilized citizenship (governmentality); continued effects of colonization, neo-colonialism, culturalism, racialization (anti-oppression theories—postcolonial feminism; anti-racism; critical race feminism); intersectionality of oppressions (anti-oppression theories); medicalization and the medical-industrial complex (political economy, anti-oppression theories). These theories also inform the practice of social research—the topic of the following chapter.

Chapter 4 Creating Collaborative Visions with Aboriginal Women: The Promise of Photovoice Methodology⁵

In this chapter I discuss the research process, the methodology of photovoice and the reflexive engagement between the phenomenal participants, the university researchers and the invested community members. I also provide a critical appraisal of cross-cultural research and using the photovoice methodology with Aboriginal women. Photovoice is defined as a participatory action research method, as well as a process towards health promotion. Participants take pictures to document their realities and engage in critical reflection individually and in a group process, using images and stories to advocate community and policy changes. This chapter focuses on some of the methodological challenges and accomplishments associated with photovoice and our project entitled *Visualizing Breast Cancer*. This research involved a research team which included me and Drs. Jennifer Poudrier and Roanne Thomas-MacLean—who have combined experience working with breast cancer survivors and using qualitative and visual methodologies. While Drs. Poudrier and Thomas-MacLean proposed and initiated this study, I managed the research and was responsible for recruitment and all forms of data collection. I discuss our collective successes as well as some of the responsibilities and risks of conducting research with Aboriginal women, including recruitment, participation, retention, community-building, advocacy and ethics. Interpretive boundaries and the “truths” of qualitative research (relative to the research setting) adds a further appraisal of the

⁵ Parts of this chapter were first published in: Brooks, C., Poudrier, J. & Thomas-MacLean, R. (2008). Creating Collaborative Visions with Aboriginal Women: A PhotoVoice Project. In Pranee Liamputtong (ed.). *Doing Cross-Cultural Research: Ethical and Methodological Perspectives*. Netherlands: Springer/Kluwer Publishers. This reproduction is done with the kind permission of Springer Science and Business media.

complexities of this type of qualitative research and the powerful lessons of research and unplanned events.

While interviews and focus group discussions have become prevalent means of collecting data, the potential of visual methods (e.g., photovoice) has only recently been realized. Current research (see for example, Wang, 2003) 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. However, to the best of our knowledge, photography has not been used in connection 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.

One of the main objectives of our larger project was to evaluate the use of this new qualitative research method of Photovoice (i.e., photography) in connection with more established methods of qualitative data gathering of interviews and focus groups). This chapter is the story of the latter—the success and challenges with this new methodology for research with Aboriginal women survivors. I begin with a brief description of photovoice as a technique, the successes, relationships developed and lessons for research related to Aboriginal women's health.

4.1 Background

Two specific domains are directly connected to the photovoice research method and this chapter: 1) decolonizing methodologies and Aboriginal women's health, and 2) visual methods. These domains provide the methodological context for my work.

4.1.1 Decolonizing Methodologies and Aboriginal Health

The history of colonization is important in the gathering of health data and has led people to be “deeply suspicious” as to how data about health is used (Marrett et al., 2004: 13). Linda Tuhiwai Smith (2005: 87) writes, “the history of research from many indigenous perspectives is so deeply embedded in colonization that it has been regarded as a tool only of colonization and not as a potential tool for self-determination and development.” There are many problems with the historical vulnerability of native peoples to scientific research which wants “to know and define the Other” (Tuhiwai Smith, 2005: 86). Visual images and pictures have also been co-opted or taken by outsiders, reproducing status quo and stereotypical interpretations.

Indigenous and decolonizing research transforms the research agendas and deconstructs taken-for granted ways of doing research—from the choice of research methods to research dissemination. Decolonizing research is connected to emancipation and cannot be divorced from the history of racism. Rigney (1999) defines three principles of Indigenist research: privileging indigenous voices, political integrity and resistance. Redefining research is also about rebuilding governance, restoring culture and enhancing community. Research in the area of Aboriginal women’s health is increasing and is geared toward improving health and contributing to the ongoing goal of self-determination within Aboriginal communities (Assembly of First Nations, 2005).

It was the position of the research team that identifying and documenting Aboriginal women’s perspectives surrounding wellness are essential to develop practices, programs and policies. Research and programs geared toward empowering marginalized

groups are effective in improving health and communities, particularly when centered on women (Wallerstein, 2006). Providing opportunities for Aboriginal women to identify and document their perspectives is essential to improve knowledge about Aboriginal women's wellness and to ensure a decolonizing approach.

4.1.2 Visual Methods:

Qualitative research is extremely useful as an exploratory approach when little is known about a topic and when it is important to draw upon participants' personal experiences (Creswell, 1998; Berg, 2004; Liamputtong & Ezzy, 2005). Within the field of qualitative research, visual methods are emerging as an innovative approach to understanding health experiences (Liamputtong, 2007). Photovoice, which has connections with feminist epistemology and literatures in visual knowledge and power, is a research tool which empowers research participants to tell their stories and to assess their own needs visually (Harrison, 2002; Liamputtong, 2007). Photovoice was successfully developed by Wang and Burris (1997) to enable Chinese village women to photograph their health experiences and transform their health outcomes. Currently, 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” (Wang, 1999:185). While Photovoice has been used in ways congruent with our research, its use for understanding the meaning of breast cancer and issues associated with survivorship and Aboriginal health has not been explored in prior research. Our project, with its roots in

Aboriginal and decolonizing health research, breast cancer survivorship and ethnicity, and visual methodologies begins to address some of the identified gaps in the literature.

4.2 Method, Overview and Steps

4.2.1 Recruitment

Participants were informed of the study in a number of ways. Articles about the study appeared in a Saskatoon newspaper as well as a First Nations newspaper. Please see Appendix A for examples of recruitment articles and informational materials. Breast cancer support groups in Saskatoon and Regina also distributed information sheets about the study to their members. Recruitment criteria were: (1) 19 years of age or older, (2) completed active breast cancer treatment at least six months prior to our study, (3) be able to provide informed consent, (4) reside in the province of Saskatchewan, and (5) identify as Aboriginal.

4.2.2 Design

At the first meeting, participants were also asked to share their story of having had cancer and these discussions were audiotaped, using a digital recorder. Participants then borrowed the digital cameras for several weeks. During the second interview, photos were transferred to a laptop computer for viewing by both me and the participant. Together, we discussed the photos and the woman's cancer experiences. The women were then asked to select several photos that they felt were particularly meaningful for in-depth discussion. This second interview was also digitally recorded and the photos were saved to the laptop computer. The final two stages involved a sharing circle and community workshop. These were opportunities for participants and community members to share participant's photographs, stories and engage in a critical dialogue towards further collaboration and

social/policy change. Each of the interviews as well as the sharing circle and focus group were transcribed verbatim.

Fourteen women initially enrolled in this study, but two withdrew due to time constraints. Overall, the data for this study consisted of 24 interview transcripts and over 200 photographs.

4.3 The Research Process: Exploring Experiences through Photovoice

4.3.1 Taking Pictures

Picture taking involved time, reflection, emotion, motivation, relationship building, risk, uncertainty and enjoyment. The depth of the thoughtfulness and creativity in their photographs was astonishing.

We expected that the participants would have the camera on average for one month and purchased four cameras. We realized immediately that taking pictures of an experience as personal as breast cancer takes time and that time is a very subjective concept. Care was therefore taken to ensure that the participants had the time they felt they needed, which meant that the research participants had the cameras between two and six months (rather than the one month, as initially intended). Some women said that the *right mood* needed to be there. Other women shared very difficult life situations, including death of a beloved family member, separation, fire and family member's very difficult diagnosis and requested more time. As researchers, we agreed that there was no way that this process could be rushed. I would check in to see how the photographs were coming and serendipitously learn about people's lives, ideas, concerns and insights about their pictures and cancer survivorship. Data collection was continuous; relationship building was an unexpected privilege.

We were concerned over the initial reaction from the women when they were instructed to use the cameras to capture their experience visually. They expressed uncertainty about what was expected from them—often asking what the other women had taken pictures of and wanting more specific instructions. One woman said: *I wasn't sure what I was going to take pictures of...how to capture life* (Sandra). Another participant expressed: *I pictured right away that it [the pictures] would help others* (Dorothy). All of the participants reflected on how much they enjoyed the experience afterwards:

This was a wonderful, wonderful exercise...(Shelley)

...it was a powerful exercise, I really liked it. it sort of helped me set some priorities; you know...what is important to me..(Shelley)

...I want to bring these pictures back to my community to show other Aboriginal women that they do not have to be as afraid of cancer.. (Dorothy)

The participants also expressed that taking pictures enhanced relationships. Families became involved as they helped create visual images and posed for pictures that were either symbolic as is seen in Sandra's picture below of "wearing hats and hiding", or taken as a reflection about the importance of their relationships, symbolized in the pictures of grandchildren and family.



Shelley said the study helped her to reflect on people and support in her life:

I really liked this exercise...I think for me it was looking over my life...it helped me to ..remember what is positive in my life, where my support systems are and what my roles are...and you know..what I could have lost or what I could lose still...those kind of things.

Mary and her granddaughter worked on the pictures together for the study. Her granddaughter took all of the pictures for her and they looked forward to spending this time together. Mary said: *...she just loved it...she would phone me and ask if she should come over and take more pictures.* She had a picture taken with her granddaughter below:



4.3.2 Second In-depth Interview

The second scheduled meeting was a semi-structured individual interview to discuss the pictures and experiences of breast cancer and survivorship. The women shared their pictures freely and discussed information within the pictures as well as “behind the images”—about social and cultural relationships which shaped their interpretation and meaning. Interviews revealed cultural protocols, relationships, creative expressions, personal stories, social analysis and limitations.

Conversations about the pictures were directed by the women. Our only specific questions were: (i) which pictures were the most important (especially because some of the women took more than 60 pictures, rather than the 10 or 12 which we initially expected);

(ii) why the picture was taken and how this relates to their lives (iii) which pictures tell the most about their experience as a breast cancer survivor (iv) which photos they would most like to share with other Aboriginal women and why; and (v) what pictures were they unable to take, but wished they could. Please see Appendix B for a copy of the interview guides.

Responses to the final question were interesting methodologically—demonstrating limitations because of time-constraints and cultural protocols. A number of women shared that they could not take pictures of natural medicines, Sweat Lodges⁶, Sun Dance⁷ or other ceremonies⁸, because they are sacred. Dorothy, for example, talked about wanting to take pictures of the medicine that she used to heal. She said she could not take these pictures because then the medicine would no longer work—its healing qualities would be given away:

There is one [picture] that I wanted to take but I couldn't. I wanted to take a picture of my medicine...our traditional way of healing..my Indian medicine..[but] ...elders don't like if you take pictures...you are giving it away..that is how elders feel when you take pictures, like they don't want pictures taken of ceremonies.. I think because they are so sacred they don't. [The Medicine]—if you take a picture it is like giving it away..it is not going to help me.. if I took a picture it is not going to help me..

A number of participants wanted to take pictures of the Sweat Lodge or Sundance ceremonies but also felt that they could not. Dorothy and her sister explained:

⁶ A Sweat Lodge is a part of many Aboriginal religious communities and is defined as ritual purification and ceremony, involving prayer and songs, spiritually connecting to the creator and the earth. The ceremony is done in a wooden framed structure designed from tree branches, using hot rocks placed inside a pit in the centre, periodically pouring water over heated rocks to create steam for purging toxins from the physical body.

⁷ A Sun Dance is a way to celebrate harmony between nature and people which involves months of dedication and mental preparation. Sun Dance ceremonies may give rise to the Powwows.

⁸ For many First Nations peoples ceremonies are a primary way to express spirituality that is innate and all-present. Ceremonies take many forms including; Sweat Lodge ceremonies, Sun Dance ceremonies, Sacred Pipe Ceremonies, fasting, feasting, smudging, quests or visions and more.

I wanted to take a picture of sweat lodge that is where I pray...but I can't take that picture ..and the Sundance for instance.. if you are taking pictures and other things other than praying or doing what you are supposed to ..if you take pictures then you might spoil it...the spirits won't be there..they won't listen or help.

Taking pictures at certain times of the year were also limited because of time constraints. Sandra shared:

...it would have been nice to take pictures of the leaves changing...to be here for another season...when you ask somebody how old they are, you're asking how many moons or how many winters they have seen I think I'm just happy to see another winter...It's supposed to snow today and I'm excited!

Some of the women shared the idea that certain images were impossible to capture.

For example, Sandra asked, how do you capture “life”?

...just doing, just being, just living...you know we stop playing because, because we're adults...the playing is such a big part of our lives and that's what keeps us young, that's what makes us feel good...laughter, simple laughter, laughter from children, it's amazing. If I could take a picture of that, you know? What does cancer mean to you? Cancer to me means life. It means enjoying everything now.

Importantly, all of the women also creatively captured emotions through their photographs—demonstrating a unique strength of the photovoice methodology. Marion, for example, captured a feeling of being blessed, represented by a picture of an eagle. She explains:

[Because of] my cultural background and my spirituality... I always see Eagles and ...like in the, Native culture, where the Eagle is a really..sacred bird, sort of thing.. I always feel blessed when I see an eagle, and I always like, know that, that um, I'm gonna be here for a while... I'm, I'm gonna, be all right. I don't have nothing to be afraid of.

She also expressed “fear” through a symbolic picture of “big black ravens”:

Before I was diagnosed with cancer they [ravens] were always on our barn all the time. They would always be by our house and, well now I'm scared

of them because, I think they represent a bad sign. Before I even knew about my cancer they used to always be around our house... and I always used to ask, why are these birds always there? They used to sit on the barn, three of them...for just about a whole year. They were always around and, and...now I'm afraid of them. That's another fear for me....because I think they represent, bad. Soon after I was diagnosed with cancer, and when I was on chemo all of a sudden like they weren't around anymore. They stopped being on the barn, like, they just fade away...

Like Marion, Cheryl captured another emotional experience, that of “anger” through a picture of crumpled paper and Sandra captured her feelings of invisibility and being exposed, using pictures of masks, hats and of herself in a tipi, as described and shown below:

Cheryl explained:

For anger, I squished up paper...and that's the only way I could describe anger, because I was angry at, at the government bodies for the way that they handled their programs...I was angry at that, I was angry that I got cancer. I was never angry that I was diagnosed with it. I just thought I can't be angry; I got it now lets just deal with it...I think my children were more angry than I was and I told them that I wasn't angry, I said I have it, let's deal with it.

About the masks, Sandra said:

there were days when I felt like I could be all crazy, messed up, but you know, there were just masks that I used to make other people feel comfortable.



Although the women directed the discussion, I encouraged the conversation to move from specific happenings and personal stories to include social analysis and steps towards possible social and policy changes. I return to discuss the layers of analysis encouraged through the photovoice methodology in more detail in chapter seven. Most of our participants moved to social analysis without any direction. For example, Sandra talked about her experiences with a group of women who had breast cancer wherein her economic realities did not allow her to follow the same course of self-care as those who were financially more stable. She suggested themes which related illness to a social, not an individual problem:

...They were talking about going on holidays like taking time off work and taking their family to Hawaii when they were diagnosed and I was like...I can only dream of that. I can't even afford the bra.

Marjorie and Margaret captured a historical and intergenerational analysis when they discussed some Aboriginal women's fear of opening up:

Marjorie: With us there has been so much intergenerational damage... everything is very hush hush...We need to tell [each other] it is ok to take your shirt off and bra off—so what if you are lop sided, you are alive...but we have been hushed...that's how I view myself--the package is a little scuffed up...but I am here...I am alive.

With photographs, the participants seemed more prepared for the interview than they would have in an interview with no visual preparation or reflection. Photographs allowed the women to direct the discussions and brought in ideas that they had thought about over the months while they were taking the pictures.

Unexpectedly, 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. The initial ethics submission ensured confidential and anonymous treatment of participants' data, to recognize the participant's entitlement to privacy and their rights to anonymity. However, as researchers, we recognized the participants' rights to be identified if they wished—especially because of the participatory and participant directed nature of this research. As such, we amended our original ethics application and this was approved. More importantly, we assert that this speaks volumes of the participants' engagement with this methodology as well as their willingness to share their lives to assist others! Please see Appendix C for a copy of all of the consent forms.

The photovoice methodology of our research allowed definitions of ethical and respectful action to be located within the social settings with the women, rather than by outsiders and the institution. Ethical principles of negotiation and mutual understanding and respect won over institutional top down decision making. This meant deadlines were pushed back in favor of understanding the importance of 'time', ethics were amended, and women were provided a tool which seems to allow a more creative, complex picture of experience. As a researcher, I also learned to listen more creatively, empathically and deeply.

4.3.3 Sharing Circle/Community Workshop

The workshop and sharing circle were at the end of the research project but represent the initial step towards participants and community stakeholders working together and developing solutions. The sharing circle was the first time that many of the

participants met to share their stories, pictures and ideas about what should happen next. This sharing circle was also an opportunity for the women to have a critical dialogue about their specific lives, discuss shared experiences and reflect more generally on concerns of Aboriginal breast cancer survivors. The workshop was an opportunity for the women to meet with relevant policy makers share stories and pictures and plan future collaboration. The workshop and sharing circle were held at Tamara's House⁹ on the same day.

The day was a mixture of emotions and happenings—unexpected, serendipitous and expected. The successes were many—including building relationships, sharing amongst the participants and with community partners, and discovering future possibilities for dissemination and continued work. There were also challenges. While our aim was for the sharing circle and workshop to be directed by the participants, there were limitations to collaboration.

The sharing circle was facilitated by the researchers, but was designed by directions taken from the women in discussions before the circle. We had numerous discussions initially with the participants about what they would like to happen at the sharing circle. Mary, for example, said:

You should have a sharing circle with the women...and you should bring in an Elder to say a prayer. With the sharing circle you could smudge everybody that wants to be smudged. We can talk about our experiences before we start looking at the pictures ...that would be the suggestion I would make...just have a day where we can spend, with an Elder somewhere...somewhere nice and peaceful and quiet and you can share, and just, spend the whole day together.

⁹ Tamara's House is a non-profit organization that provides services for sexual abuse survivors. Tamara's House was chosen because the location is in a quiet residential area, the staff are warm and welcoming, many of the women had been there for a prior interview and the room they offered had large comfortable armchairs, arranged in a circle.

Most importantly, they wanted the sharing circle to be an opportunity to meet each other, share photographs, stories and create connections. Many participants expressed the importance of having support from other Aboriginal women who have experienced breast cancer, yet most of the participants did not have this opportunity. Tina, for example, told us that:

I would have loved to see another brown face in [the hospital], not that I'm racist or anything like that, I just needed to see another...

Our research team prepared numerous gifts for the women, in addition to an honorarium. We purchased photo albums and filled these with pictures. The albums contained all of the participant's photographs as well as five pictures from each of the other participants. Poudrier prepared a DVD (photo story) with a slide show to music, displaying the women's photographs. We felt uncertainty here, hoping very much that all of the women would enjoy the DVD, albums chosen and display of their pictures.

We began the day with a Morning Prayer. Each woman had about 10 or 15 minutes to share their stories and photographs with the other women in the sharing circle. This was followed by a free flowing discussion of shared experiences, shared concerns and shared ideas about how to continue to support each other as a group and how to use their experiences, photographs and lives to assist other women newly diagnosed and other survivors of breast cancer. The general tone of the sharing circle was one of warmth and sharing. The women all expressed how happy they were to meet each other and to have an opportunity to share each other's stories and lives.

Interestingly, the sharing circle was the last step of the funded research by the research team, but the first step of the coming together of women who now have been

offered an opportunity to take what has been established further. It is for these reasons also that the second part of the day was dedicated to a community workshop, to which invested community members were invited.

To ensure that participants in our project were offered an opportunity to meet with relevant policy makers, connections were made (by the researchers) with the Saskatoon Health Region, Breast Health Center in Saskatoon (BHC), Breast Cancer Action Saskatchewan (BCAS), Breast Cancer Community of Stakeholders and Indigenous Peoples Health Research Center (IPHRC). All of these agencies have expressed an interest in the findings of this research and in services that may better meet the needs of the Aboriginal women breast cancer survivors. These advocates were chosen by the university researchers, not by the women themselves. We chose the advocates for a number of reasons. First, we did not have the privilege of consulting as a group before the sharing circle. Second, identifying community advocates early meant increased support from the community throughout the initial data collection stages.

The outcomes of the initial community event are discussed in detail in Chapter 8. Briefly, relationships were established between Aboriginal breast cancer survivors in Saskatchewan and between the interested community members. Findings were disseminated to the community members and a number of very ambitious directives were established. The directives included: fundraising initiatives, photo exhibits and ways to keep this group of women together and growing, to support other newly diagnosed Aboriginal women with breast cancer and breast cancer survivors.

4.4 Discussion

Our findings suggest that photovoice methodology is an empowering method suitable to completing health research with Aboriginal peoples—especially considering deep concerns about the historical link between colonization and researching a population whereby many have said on numerous occasions: “We’ve been researched to death” (Schnarch, 2004: 3). Identifying Aboriginal women’s quality of life and breast cancer survivorship concerns from their perspectives (privileging their voices and visual images) has contributed to knowledge about Aboriginal healing and health in a way, which privileges Indigenous voice, respects diversity, benefits the women individually and enhances community’s strength.

Our findings suggest that photovoice is culturally appropriate and suitable to health research with Aboriginal women for a number of reasons. First, through photovoice, participants express that they benefit individually, relationally, socially and politically. Second, data collection was done in consultation with the survivors. Third, to ensure proper analysis of the data, we continue to see ourselves as learners, not “experts”. Smith (2006: 98) defines this as a “community-up” approach for researchers.

4.4.1 Individual, Relational and Political Benefit of Photovoice

The photovoice process is informed by the participant’s own stories and pictures, ensuring empowerment to groups whose voices and pictures have been co-opted in mainstream research. Previous photovoice research agrees that participants benefit personally and relationally. In the *Language of Light* photovoice project (Wang, 2003), for example, both women and men noted that participation enhanced self-esteem, quality of life and status with peers. Their participants spoke of enjoying the creative process and the

attention they received from policymakers, researchers and the media.¹⁰ A sixty-year-old woman held up her camera and said “This is history!” (Wang, 2003: 187). Relationships also develop through the participants both working on their photographs together, as well as through the group sessions that occur. Wang (2003: 190) said about their research:

Participating in this project itself enabled participants to get to know one another, build ties and friendships, and therefore bond as a peer support group for problem solving and teamwork...this enabled homeless people to speak from their experience and talk about what mattered to them so that they could help one another survive.

In the VBC project, all of the women enjoyed the process—the personal and social reflection, the creative component, the relationship building and especially the potential of the photographs to assist other women who may experience breast cancer. As noted, Shelley said: *this was a wonderful, wonderful exercise*. Dorothy expressed: *I pictured right away that it [the pictures] would help others*.

Finding solutions together is a theme of photovoice. Ellen Lopez, Eugenia Eng, Elizabeth Randall-David and Naomi Robinson (2005a: 113) describe one woman’s response to another photovoice project: “It was beautiful. We learned we can learn from each other and we can work together. From this, we can do anything”.¹¹ In our VBC research, the women often enjoyed working closely with their families as they took the pictures. The workshop and sharing circle was the initial step towards the VBC participants

¹⁰ One fifty year old man stated that “many shelter users were intelligent people seeking to be engaged and stimulated by training such as that provided by the language of light photovoice project.” (Wang, 2003: 187). Had he not participated, he said he would have been “just lying around watching television” (2003, 187).

¹¹ Another asset of photovoice is that it is accessible to anyone who can learn to use an autofocus camera. Participants who cannot read or write may also experience esteem from participating. Wang and Burris (1997), for example, describe the success of photovoice methods with women of low income from Yunnan villages, where female education was lacking support, both parental and broader community support.

working together and developing solutions, since this was the first time they had the opportunity to meet. The women together established very ambitious directives, including a photo-exhibit, creation of a new DVD or video, fundraising and establishing further support for other survivors and themselves.

A goal of photovoice, and a key component of research with Aboriginal peoples, is that participants also benefit from their involvement socially and politically. Participants are empowered to represent and also enhance their communities through the documentation of their life experience through photography (Wang and Burris, 1997).

Moffit and Robinson (2004: 2) say this clearly:

With this technique, people capture images of their everyday life experiences in their communities through the use of a camera. By telling the story behind a photograph, they describe life in their communities and thus convey to others the context of their lives from the personal points of view.

Community members are thereby offered an opportunity to assist in the development of relevant policies. In the VBC project, the women met with relevant policy makers and have the opportunity to use their pictures towards increasing community health.

As mentioned policy makers in the VBC project were chosen by the researchers, without consultation by the participants. Lopez and colleagues (2005) suggest that advocates should be identified through consultation with the women, especially because of the inductive nature of the photovoice method. They explain:

...if advocates had been identified at the outset of the project one obvious choice would have been to recruit a representative from the local cancer support agency. Yet nobody from the agency was identified by survivors as an advocate. In fact, survivors indicated that they rarely used the agency's resources because they perceived that it catered solely to white women (Lopez et al., 2005a: 342).

On the other hand, it is recommended by Wang (1999; 2003) and Wang and Burris (1997) to identify and recruit community partners early in the project—as a community building strategy. We chose the advocates for a number of reasons, both intentionally and due to circumstance. First, we did not have the privilege of coming together as a group initially, or for more than one session. Second, identifying community advocates early meant increased support from the community throughout the initial data collection stages, as discussed earlier. For example, Breast Cancer Action Saskatchewan shared stories about the study in their newsletter. Lori Chartier (Project Manager of the New Breast Health Center, at the time) became the principal community led applicant for the community partner for an IPHRC grant (to extend VBC), and advocated on behalf of the VBC participants to have their sharing circle funded by the Saskatoon Health Region (which it was). Peg Schmidt, community consultant and advocate for the Breast Cancer Community of Stakeholders acted as an advisor to the project and a consultant for review and evaluation strategies and for strategies of care for Breast Cancer Survivors. Rose Roberts, Peg Schmidt and Tia Lutz all became community co-applicants for proposals to extend the project. Elder Maria Campbell, an elder for the Indigenous People's health Research Centre acted as a consultant throughout and invited women to be participants, through a personal story she wrote in an Aboriginal newspaper and speaking engagements.

We have learned that it may have been more ideal to meet with the women as a group more often, furthering consultation. The project, however, has new legs now, allowing future development by the participants of VBC and the breast cancer and research community. New community partners will be established by the women (and through their relationship with existing community partners) and ideas for policy initiatives and

community education have begun. The research team also has an opportunity to broaden the scope of the research to remote Saskatchewan and national levels.

I recommend in future research with Aboriginal women that policy makers are chosen in consultation with the participants—towards a more inclusive community-based approach. Because the women did not have a prior connection with these stakeholders I question if an ongoing collaboration is possible without the continued support of the research team. This would have to be built into the funding structure. Consulting with the participants at every step of the research project is even more important when participants are Aboriginal and share distrust in the research establishment based on historical treatment and oppression.

I recommend that future research with Aboriginal peoples follows the revised model of photovoice research put forth by Castledon and Garvin (2008). This model ensures that photovoice is not only a participatory research method, but incorporates procedures of a community based participatory research method (CBPR). Wang's (2005) approach and other photovoice research projects do not involve extensive discussions on community building and trust (Castledon and Garvin, 2008). I argue that our photovoice method would have been more successful with Aboriginal peoples, especially towards satisfying social and community benefits, by including CBPR processes which aim to build trust, create sense of ownership and balance power between researchers, community members and stakeholders. Wang's stages and our research focus on the following stages: recruitment and training; photography assignments; in-depth photography interviews; critical group contextualization and focus group; and reaching policy makers. The tools Castledon and Garvin (2008) include are: ongoing consultations with participants, both

individually and within photovoice groups; ongoing participatory analysis of the photovoice process; and ongoing participatory data analysis. They suggest that this be repeated for at least six months.

4.4.2 Data Analysis: Researchers as ‘Learners’

To ensure participatory analysis of the data, as researchers we also continue to see ourselves as learners, not “experts.” The point of this research is to learn the perspective of the Aboriginal women survivors. The analysis involves deconstructing subjectivities and understanding this in the context of how individuals make meaning and create identities. Reflexivity is therefore central—as our own subjectivities and identities also influences the research. The creation of knowledge and the research process is, therefore, intersubjective, acquired through the interaction of the researcher and the research participants (the survivors) and the interaction between the survivors.

The meanings within the photographs are also intersubjective and layered. The visual images were read by the women by looking internally at the meaning presented by themselves and by looking more externally at the image, examining how she chose to present her content—and what the action of taking of the photograph included (i.e. family and friends participation in this process, cultural protocols and more). The visual images are also read by researchers and the participants examining the social and cultural context of the images that are presented. This involves the women’s interpretation of what lies behind the image.

Interpretation of photographs within sociological research has often been done using a positivist paradigm—as a way to provide evidence for so called “objective research” (Stasz, 1979). This is shifting, however, to a recognition that photographs may

offer perspectives that are different, provided by the individual who is taking the picture—realizing a more social constructionist view (more accommodating to decolonizing methods) which understands the meaning of the photograph from the taker (see, for example, Tagg, 1988). The VBC project is informed by this social constructionist (and anti-oppressive) view, whereby the women’s interpretation is viewed as being the most important. In addition, however, both the women and the researchers (as well as any other people who view the photographs) all bring their own social position and specific interests to the interpretation of the photographs. In this way, it is also important to recognize where researchers and women are situated. In other words, as sociologists, we recognize that the pictures are recording interpretations and experiences of individuals within specific cultural and social positions. The task is as much to understand the individual representation and interpretation, as it is a social interpretation of the women’s and researchers’ positions in the social world and how this shapes social reality.

4.5 Synthesis

Through this research, the participants, university researchers (ourselves) and community partners, together (in a self-reflexive way) have participated to create a new understanding of Aboriginal women survivor’s lives through collaboration. Despite challenges and unexpected occurrences, this project seems to have provided an essential first step in supporting Aboriginal breast cancer survivors in Saskatchewan, affirming their experiences, building collaborative relationships between the women and community partners and raising awareness of survivors’ experiences.

The assets of using this method are clear to us. The method of photovoice empowers participants to share an understanding of their needs and share stories and

narratives visually—privileging indigenous knowledge, validating diversity of the participants and deepening opportunities for participants and researchers to explore personal, social and political experience and wisdom. The visual images draw out difficult experiences as seen throughout the dissertation—needs and essential supports. Another key asset is that it brings forth positive health indicators—evidence of strength, resiliency, spirituality, family and community. The camera seems especially motivating and captures what the women see as important, prioritizing knowledge from the community. However, there are also key limitations of this method.

First, the motivation, time and thoughtfulness the women contributed for the VBC study is heartening. This also demands that we ask, however, if the VBC photovoice participants are representative, or how can more voices be shared? The second limitation concerns the connection of photovoice methodology to social policy. Minkler (2000) 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. This critique includes my recommendation that photovoice with Aboriginal people be modified and include steps from community based participatory research projects. Key here is that participants and researchers (and community members) continue to discuss how visual images and narratives are understood through the photovoice method (Wang, 2003). This critique of photovoice is deepened through a lens of anti-oppressive and critical theory, developed in detail in the final chapter on policy implications and empowering methods.

In closing, the participants (researchers and community advocates) have all expressed that they benefited from and enjoyed the creative process and the potential this

work has towards helping newly diagnosed women and other women in similar situations. Our approach affirms that the best way to learn about health experiences is from the participants (Moffit and Robinson Vollman, 2004). In our study, this means learning from the Aboriginal women themselves. Importantly, the ways of knowing by First Nations peoples have been stripped through colonization. We suggest that photovoice may be used to reclaim these points of view and, therefore, be seen as having potential for decolonizing research (Smith, 2006). A further critical assessment of photovoice and empowerment methodologies is offered in Chapter 8.

Chapter 5 Visualizing Experience: Resilience and Prominent Social Forces

I could go out in public now and I could talk about my breast cancer, whereas before, I couldn't even say breast cancer. I couldn't even say it. (Marion)

In Chapters 5, 6, 7 and 8, I present findings from research with Aboriginal breast cancer survivors beginning with their own words and pictures. My interpretation of the women's stories resulted in four general themes which I explore herein: 1) psychological and physical role adjustments; 2) importance of support; 3) identity and cultural safety and 4) personal and political advocacy/policy directions. In this chapter, I focus on the first theme, psychological and physical role adjustments focussing specifically on: 1) fear, anger and isolation; 2) resiliency and hope; 3) humour, personal philosophy and life purpose; and 4) history and spirituality. I move from these particular experiences of the women to their own analysis of the social context, drawing links to the social-oncology, epidemiological, sociological and anti-oppressive literature. The emerging framework recognizes three prominent social forces—cultural and historical experiences/traditions and culturally

derived meanings of identity and sexuality; racism and racial stigmas; and socio-economic inequalities—all which impact physical and psychological well being and identity of the participants. My findings reinforce the importance of studying the intersection of gender, race and class on survivorship experience.

I draw on the definition of cancer “survivorship” by Fitzhugh Mullan (1986), who was himself a physician and a cancer survivor. He was the first to coin the term “cancer survivor”, in his article “The Seasons of Survival: Reflections of a Physician with Cancer.” He defined a cancer survivor as an individual who is “living with and beyond cancer” (Mullan, 1986) and this continues on today (Fobair, 2007). Being a survivor is often felt to begin after the completion of treatment, however, it is also applied from the moment of diagnosis, through treatment and an individual’s life. This term also includes caregivers, family members and friends who are affected. I combine this definition with a sociological understanding of survivorship as multi-dimensional and context dependent. My writing therefore reflects a subjective perception of survivorship, which is influenced by shared experiences, social norms, values and beliefs, which are in turn influenced by cultural, socio-economic and ethnic factors (Hassey et al., 1996; Hewitt, Breen and Devesa, 1999; cited in Lopez, Eng, Randall-David and Naomi Robinson, 2005). The interviews were transcribed and coded using NVivo version 2.0, a qualitative data analysis software package. Detailed coding and the coding framework was determined using NVivo and in discussion with the research team as well as some discussion with the research participants. I began the development of the framework as the conceptual relationships became evident.

That the women were themselves moved to discuss the social context of their lives is understood as a benefit of the photovoice methodology, which is argued to facilitate a

layered window into people's worlds. The women's knowledge is not only a subjective description of their own lived experiences, but also an insight into situated and subjugated knowledges (Hill Collins, 2000; Harding, 1987). Situated knowledges are experiences of privileges and/or oppressions, which means, for example, that someone has to have the experience of being racialized in a society, to know what that means and each experience is different (Moosa-Mitha, 2005). An awareness of subjugation, from lived experiences, is also defined, for example, by bell hooks (1992) as having a "translated/subaltern" knowledge—whereby the women are aware of their own understanding of this world, but also of mainstream and dominant knowledges. As a learner (researcher), I recognize that this knowledge is owned by the women (Dominelli, 2002).

5.1 Distress and Social-Oncology

*...at one point I couldn't talk about it at all. I would and my tears would come...
I, I've never cried so much in my entire life.*(Tina)

There is a picture of cancer within the media of women who are unremittingly resilient and cheerful but this picture seems over-stated. Although women show resilience and strength, problems persist. There is an abundance of literature on breast cancer, including longitudinal studies that demonstrate types of distress and disruptions that occur (Wong and Bramwell, 1992; Vickberg, 2001; Stanton et al., 2002; Polinski, 1994; Meyer et al., 1998; Lasry and Maregolese, 1992; King et al., 2000). Less discussed in the literature are the links between the psychological experiences of fear and their association with culture, class, gender and race (Thomas-MacLean and Miedema, 2005). Themes here are distress, fear, shame and isolation associated with this disease.

These themes are connected to literature from socio-oncology which suggests that understanding the distress related to being diagnosed with cancer has offered health

professionals more tools to help people cope (Fobair, 2007), or at least allowed them an opportunity to engage with them about their fears. Bettelheim (1981; cited in Fobair, 2007: 15) shares findings from his research with cancer patients: “The shock of hearing that they have a cancer diagnosis leaves many patients feeling “wounded” and “out of control.” Other research also discusses feelings of isolation and a fragile sense of inner well-being. Bettelheim, (1981; cited in Fobair, 2007: 15), for example, states: “The aura of well-being within a person can be destroyed. One’s inner attitude towards life is perhaps more fragile than we tend to recognize.” Many of the VBC participants shared feelings of distress, fear, and feeling *out of control* and *isolated*, paralleled in the social oncology literature.

5.1.1 Feeling Fearful

The women spoke of their fear associated with diagnosis and said their fear was *devastating* and often linked to death and dying. Marion, for example, expressed that she never thought that cancer would happen to her and was totally devastated, linking it to *death* when it did:

...all I thought about was death. That’s all I thought about and I realized that after a while like, it’s not necessarily a death sentence. Cancer...

Sandra also associated fear with dying and describes feeling 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 and you poke your baby... You know my mom died. And my divorce fell apart...I just, I have never been that afraid in my life. I was so scared at the beginning [when I was diagnosed].

Although participants expressed that it was difficult to find pictures to visualize this strong emotion of fear, their words seemed to craft images. Other powerful imagery were

reflections of *spinning*, being *wounded*, *isolated* and feeling *out of control*. 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 in, where I was going. It took some time. I don't know that I still know where I'm going. I just, I've stopped spinning anyway, I know that.

The findings from the VBC research reinforce the conclusions in the socio-oncology literature (see, for e.g. Fobair, 2007) on the fragility of an individual's sense of inner well-being and the very strong fear associated with cancer diagnosis as well as fear of recurrence.

5.1.2 Fear of Recurrence

Modern treatment means that more people are surviving breast cancer, which also means many women are living with the risk and persistent fear of the disease returning. Fear of recurrence is talked about in the medical literature as being almost universal, persisting for many years after cancer treatments are finished (Simard and Savard, 2008). Studies on fear of recurrence for breast cancer have found from 22 to 99 percent of survivors experienced fear of recurrence and that this is commonly reported as an important problem (Humphris et al., 2003; Leake et al., 2001; Lee-Jones et al., 1997; cited in Simard and Savard, 2008).

The fear that plagued many of the VBC women was not just upon first diagnosis but persisted throughout their treatments and after they were said to be in remission. Many of the women talked about how common everyday occurrences such as; finding a freckle, developing a cold-sore, or having a sore throat, have become a source of fear. One woman 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. I uh, you know whenever something happens... the first thing that comes to my mind is cancer. (Sandra)

Another participant discussed how frightened she feels when she gets a cold or the flu.

Knowing that it does not make logical sense, she said that she experiences every cold like it is her first one:

Oh I think...always if I get a cold... it seems that I'm looking at my cold for the first time in my life, that I've never had a cold before. So this is unusual. And so, it must be my cancer coming back. (Tina)

Using winter and herself in a tipi as a powerful metaphor, Sandra demonstrates how she views fear and cancer recurrence. Standing below in the picture of herself in the bare tipi, she said that this symbolizes feeling exposed to cancer all of the time—even though she has been in remission for a long time. Also, for Sandra, winter is a time when everything is sleeping. Cancer is also sleeping:

...I wanted to take this because it's like, winter everything's sleeping. Like for me, 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.



Amongst cancer survivors more generally, although the fear of recurrence may lessen over time, it is said not to surcease (Aufdenkamp, 1997; cited in Thomas-MacLean, 2001).

Fear and fear of reoccurrence was articulated more strongly for some of the VBC participants than others. Methods of coping with distress and fear also varied amongst the women.

5.1.3 Coping with Distress and Fear

Although the majority (all but one) of the women expressed feeling fear or out of control, their perceptions of how to deal with fear were expressed quite differently. The women spoke of themselves and others coping with fear and distress through: expressions of anger/crying; hiding fear and distress from their families; spirituality and symbolic representation; denial and alcohol; and strength and resilience.

Three of the women hid in the bathroom and cried by themselves (one participant kept the water running). They did this so that they would not scare or burden their husbands, children, and foster children. Marion talked about crying all of the time:

Like all I did was cry, cry, cry...I was scaring my family when I was always crying. So I got to the point where I'd go in my bathroom and that's where I would cry. Like anytime of the day, in the middle of the night, like I would just go in there and cry because I was so scared.

Marion associated her fear with the presence of ravens around her home. She visually expressed this through a picture of *big black ravens*. Ravens were always on her barn and by her house prior to her diagnoses and she became scared of them and what they represented:

...I'm scared of them because, I think they represent a bad sign. Before I even knew about my cancer they used to always be around our house...that's another fear for me...because I think they represent, bad. Soon after I was diagnosed with cancer, and when I was on chemo all of a sudden like they weren't around anymore. They stopped being on the barn, like they just fade away.

Marion's picture of the raven advises of symbolism of animals, in addition to her inner feelings. When ravens were surrounding Marion's home, her fear increased. She felt comfort when they disappeared, knowing that she was healing. Although she said she often felt *hopeless*, other animals (such as the white fox or eagle) were symbolic of hope.

Participants also spoke of family and friends, both on and off reserves, who coped with their breast cancer diagnosis using alcohol or other methods of denial. One participant spoke about drinking day and night for two months, *maybe longer*:

The times that I was drinking I was...in my own mind...[I had] made up my mind [I] couldn't quit...But now... I said what's the sense for me to try and kill myself or commit suicide a lot earlier when I know I'm dying anyway? My drinking is not gonna help me any. So, I had about three quarters full of 26 ounce of whiskey and I said...I got to live for my children and my husband... (Margaret)

There was grave concern by all of the participants that women may avoid their illness through drugs and alcohol and therefore not seek services or support.

Although this work does not speak to the specific impact of psychological well-being on health outcomes, I suggest that it is important to consider new medical research in relation to distress, fear and coping. I will also suggest in a moment, however, that socio-oncology and medical research would benefit from including a psychological and sociological analysis. Psychological adjustment is important in its own right and other medical consequences make this even more important. New psychological and medical research on the physiological effect of distress and depression indicates these symptoms may also worsen health outcomes. Watson et al., (1999), for example, argued: "patients having high levels of hopelessness and depression do not survive as long as others do" (cited in Sing and Verma, 2007: 64). Research on breast cancer and the fear of

reoccurrence, alongside depression has found that these symptoms may lead to poor health outcomes (Stanton et al., 1998; Watson et al., 1999). Depression and fear have important medical consequences and are said to affect things such as functional problems, arm mobility and tumour growth. “Patients having high levels of stress and do not cope well show poor immune system activity and some evidence suggests that cancer worsens more quickly if immune functions are impaired” (Redd et al., 1991; cited in Sing and Verma, 2007: 64). This literature also suggests that psychological factors contribute to exposure to carcinogens (i.e., smoking, drugs and/or alcohol) (Sing and Verma, 2007: 64).

The use of alcohol to cope with a diagnosis of cancer is also discussed in medical literature as creating more problems for patients, including their perceptions of suffering and on the patients’ caregivers and families (Passik and Theobald, 2000). This literature suggests that family members with chemical dependency often form a fragile support network and may already be quite “burned out” from realities of living with someone with addiction. Passik and Theobald (2000) argue that families’ patience with members who live with addictions can be limited. Passik and Theobald (2000) have suggested that if patients can be empowered to control alcohol use, by working with a specialized team and that this may also assist in their ability to cope and cope with their cancer. Part of this is from the pride experienced through even limited successes when dealing with addictions. The lack of specialized support services on reserve for the women who are dealing with both addictions and cancer are an important concern, as are problems with addictions on reserves—showing how race and geography may affect well-being and cancer survivorship, reinforcing that the story must shift and consider underlying social forces.

5.2 The Shifting Story: Race(ism), Gender and Socio-economics

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...(Cheryl)

As outlined in Chapter 2, literature within social epidemiology goes beyond biological understandings of medical knowledge. Illness and health are contextualized within cultural, social and economic locations. I argue that this literature introduces key concepts which parallel the VBC women's stories and is key in understanding Aboriginal women's experience of health and breast cancer, distress, fear and resilience. The social distribution of human health, illness and death are linked to material and social conditions, specifically 1) socio-economic; 2) systemic racism and living on reserve; 3) discrimination and racism; and d) colonial marginalization.

5.2.1 Survivorship and Socio-economics

Fear and anger were very much related to the lived realities of socio-economics as well as experiences associated with being an Aboriginal woman. The women talked about socio-economic status, losing income, and raising families as sole supporters. These concerns, along with issues surrounding government support, such as Employment Insurance and social assistance all affected their survivorship experience. The VBC women's stories and visual images reinforced the tremendous impact of different financial realities on survivorship and well being.

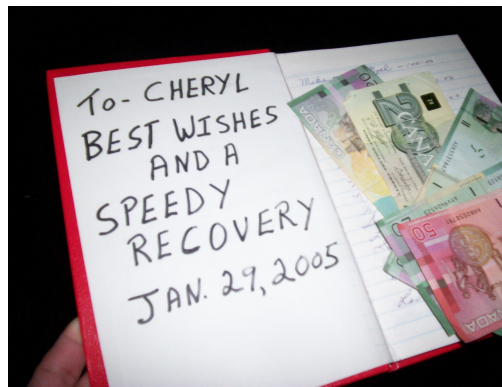
Cheryl said that losing her source of income and the limitations in Canadian employment insurance was more difficult than her treatments for cancer. Cheryl had her Employment Insurance cut off, was declined by the Canada Protection Plan, and Community resources all within two weeks:

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

Cheryl's situation made me wonder what would have happened to her if it were not for the kindness and gifts from her rural community, and what would happen to other women whose communities do not so readily respond to the needs of community members.

Cheryl's community held two fundraisers for her after she lost her Employment Insurance.

She demonstrates this visually below:



The VBC women who lacked resources and were on social assistance when they were receiving treatments also talked about not being able to afford certain recommended foods. The women overwhelmingly felt that socio-economics was an important factor related to survivorship and that these realities increased their fear towards being able to care for themselves and for their families.

My findings here concur with the results of research which show a need to develop more experiential knowledge of women who suffered social problems related to economic and racial barriers (Gould, 2004). As discussed in Chapter 2, much of the literature on class, socio-economics and breast cancer reveals financial need for cancer survivors through treatment and diagnosis (Kasper, 2000). Financial need during treatment and survivorship is strongly reflected in my findings. Many of the participants, including those

who were employed full time when they were diagnosed with breast cancer, expressed financial worries.

In addition to socio-economic concerns all of the women felt that their stories must include information about women who live on reserves. Issues important to address included: social and environmental problems on reserve; access to affordable healthy foods and support networks; lack of medical taxis and transportation for treatments.

5.2.2 Systemic Racism and Living On Reserve

Many Aboriginal people are located on the margins of the political economy, which is argued to be related to their unequal health status (Browne and Fiske, 2001). This is especially true for First Nations people who live on reserve (Sinclair et al., 2006). On reserve health is linked in critical literature on Aboriginal peoples health to the effect of colonization and neo-colonialism including problems with housing, environmental concerns (Sinclair et al., 2006), a history of displacement through forced reserve communities, residential schools and socio-economic conditions. Although only a few of the VBC women were living on reserves, all of the participants discussed deep concerns about those women who were. Isolating conditions, poverty, family crisis, and problems with alcohol were viewed as hindering women's ability to seek medical information or attention and causing deeper distress.

Dorothy said that she moved into Saskatoon during her treatments because of the poor living conditions on her reserve. Through her pictures, she described the housing, her 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 for, since it was new. And I'm living in that house, and I've been telling them...And that's, that's my heat, for winter time...a wood...the same thing, old...with the house there, fifteen years...I've been asking for them to buy me a new stove.



Dorothy was seen in her community as an activist and leader. When she talked about the conditions of the water, environment and community facilities, she had been actively trying to better her communities for many years. Dorothy recognized a strong connection between cancer and the environment, the water and unused community facilities. Like many of the women, she spoke not only out of concern for her own welfare:

...the water's gone, I think it's maybe contaminating some, some place. Some houses, like there's these two other women there that had a, one has leukemia...And they, both, lived in the one, the same house...And when I was doing, when...a protest.... Taking pictures of everything, houses and.... and how they, how they look inside ...one, one house ...I went in. I went and looked in that [water] system...they haul water there... but I went and looked in that there's...lots of stuff there...that you can't imagine. Like a, there's an old... And there's a lot of deaths that can be... these homes...And that's what, that's what really bothers me.



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:

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

Cheryl talks about her own experience, being from Muskeg Lake First Nations and their medical taxi service that she was approved to use. She said she would use the taxi for the drive in, but on the way home it was better for her to be with somebody that she knew:

If I got sick on the way home I didn't want to be sick with a taxi driver that I didn't know that well. (Cheryl)

Food availability, crisis in communities, violence and relationships were all talked about as playing a role:

...I mean you can't tell somebody who lives up in like, Fond du...[where it costs] like twelve dollars for milk or...like how do you, 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, to reduce your stress... I think that programs and things when they're dealing with Aboriginal people, they need to be realistic and look at, the issues that are really facing them, you know the stuff, like whether it's poverty or abusive relationships or FAS or you know, there is all of these other things that can come in that are, they're very prevalent in First Nation societies. (Sandra)

I argue that the experiences of the women in this research reinforce social epidemiological literature summarized in Chapter 2, which suggests that resources such as knowledge, power (Bolaria and Bolaria, 2009) as well as quality housing and healthy environments allows people to avoid risks of disease (Poudrier, 2003). All of the women felt that their stories must include information about women who live on reserves—

whether they have lived on reserves themselves or were concerned for others. Racism was also a key factor in this discussion.

5.2.3 Shared Experiences of Racism and Discrimination

I would have expected that the above concerns regarding environmental conditions, housing, socio-economics and social problems may be more straight-forward to visualize than personal experiences of discrimination. Pictures and stories about personal experiences of racism and discrimination were, however, very powerful and forthcoming. For example, Sandra talked about continued racism throughout her life and how this affected the trust she felt towards others as well as her own identity:

...growing up as, as an Aboriginal woman in Prince Albert I mean there's very, dealing with the racism and stuff like...that's something that was part of my everyday life. But so, it was hard to go to, to look for help with people that I didn't really have trust for already. (Sandra)

Racism and the fight against racism are expressed through their photography—symbolically as ‘fighting against it’, and through imagery of treatment and experience. Sandra’s grandson is seen doing a karate step out of the box, symbolic to her of a brighter future, fighting against and being free from racism:



So you know, my future is looking brighter....you know that, that we're gonna break away from all of these horrible things... Racism, like you know whatever they are... And he's gonna make it better.... I just thought he was handsome and brilliant.
(Sandra)

The women shared experiences of racism inside and outside of the health care system and tied these experiences to their identities, Othering [without using this language] and showed the relevance of socio-epidemiological literature which links the impact of racism and discrimination to health outcomes and survivorship experiences.

5.2.4 Social Location and Colonial Marginalization

Many of the women situated their everyday lives, including experiences of racism, violence, socio-economic realities, fear, silence and anger within the continued effects of colonialism and systemic racism. They defined their own and others health needs as well as resiliency and strength in this very complex way.

Margaret and Marjorie, for example, talked directly about the intergenerational impact of residential schools and the loss of culture and what this has meant for her health and others' health and well-being:

I've been an urban Indian for thirty five years in Saskatoon... people with Masters, with PhD's...they have lost their identity... and parents have lost their parenting skills... and ours go back to years ago from uh... residential school survivors... And this I call it...generational impact on....my age, in between fifty and sixty, we have lost our parenting skills, and that intergenerational impact, that is on all walks of people.

Marjorie talked about how violence against her at the residential school contributed to her resiliency and strength to be able to overcome and fight against her cancer:

... in boarding school, they could say oh you're this, you're that, you stupid, whatever... like what you tried to beat down in me, you brought something up that's been hidden right along and brought it up and I'm a better person for it.

Other women interpreted behaviours such as silence and anger, said to be typical of Aboriginal women, as also linked to historical oppressions. The women spoke of the silencing of many Aboriginal women (on and off-reserve) over time, linking this to historical assimilation, residential schools, day schools, histories of violence and continued racism. Silence is said to be part of the accumulated affects of historical burdens of colonization and continued racism. This is talked about again in Chapter 7.

It seemed that many of the women had been hurt by discrimination and racism their entire lives. Many of these women survived residential schools and systemic discrimination inside and outside of the health care system.

In sum, as outlined in much of the literature on racism and health (Nazroo and Williams, 2006; Conley, Strully and Bennett, 2003), structural and institutional racism, which plays a role in economic and social disadvantage, can be viewed as centrally connected to health and well-being. These women addressed problems with: on reserve housing; water quality and other environmental concerns; accessible health care in rural areas and medical-taxi services; and socio-economic, financial issues and health inequalities.

Variability of experience of the participants and the diverse, but important, influences of social realities was also shown through their resilience and the factors which they attributed to their strengths and hopes.

5.3 Resiliency, Strength and Hope

I learned that you have to be positive and strong, in order to survive. If you're going to ... say, okay, I'm gonna die... you're gonna die, because you're not fighting.
(Marjorie)

Definitions of personal resiliency vary and the social constructionist literature points to resilience meaning different things for different people (Unger, 2006; 2001). The definition of resilience which I argue resonates best with the women's stories, means that the participants have had the ability to cope and thrive despite their illness. Denz-Penhey and Murchock (2008) define personal resiliency as having a strong connection to life and relationships, where illness becomes secondary. Each one of the participant's stories included stories of such resilience, both personal and within their families. For some, resilience was evident throughout their illness, and for others, resiliency was enhanced or developed throughout illness, recovery, and survivorship.

5.3.1 Resilience Throughout Illness

The participants talked about maintaining a positive outlook throughout diagnosis and treatment. For some women, this meant having a positive attitude right from their diagnoses. For others, resilience and finding a positive attitude were learned throughout the cancer experience.

Shelley explains that she approached her diagnosis and her surgery with a very positive outlook.

...the following Monday was when my surgery was booked and, and in that four weeks... I knew I was going to have surgery and... I could ...I mean, I had no problem concentrating in school or any of those kinds of things...I went in there with, a real positive attitude...

Shelley attributes some of her own positive attitude to her daughter's partner who maintained a very positive attitude even though she was given a ten percent survival rate.

Shelley said: *...And how positive it was, so, I just thought, if she can do it, so can I.*

Marion and Cheryl talked about working hard to prepare themselves emotionally and learning to have positive attitudes. They both felt that their attitudes would change the outcome of their illness:

How you go through it, is how you survive. That's what I learned, that, I learned that you have to be positive and strong, in order to survive if you're going to go and say, okay, I'm gonna die... you're gonna die because you're not fighting. That's what I learned. It's like it was hard but, I had to learn so much by myself I...
(Marion)

Cheryl talks about preparing herself emotionally, like preparing for the *Olympics*—and how important thinking positive was for healing her body:

I had to... prepare myself emotionally and to be able to do that I had to work on the positive route. And I knew I had to think positive for my body to heal properly. You know it was a mental, and also like getting ready of the Olympics. I started preparing myself to have a stronger body. I did a lot of walking and a lot of positive...thinking.

The women shared profound resilience throughout their illness experience. They also shared ways that resilience was enhanced during and because of their breast cancer.

5.3.2 Resilience Enhanced During Illness

Cancer was really a blessing in my life...a new insight...(Sandra)

Many of the participants did find benefits from the experience of breast cancer. All of the women said that this experience either, enhanced their relationships, shifted lifestyles in a way that they were living more according to their true priorities, and/or deepened their appreciation of life. Although the women didn't want to be told to look on the bright side, many of the women expressed that they did find a bright side. What follows is a collection of the perceived *benefits* of cancer and what I argue is a profound visual look at resiliency—deepened connections to life and relationships throughout a devastating illness.

The symbols the women used in their pictures expressed meaning which identified a sense of shifting purpose within life and understanding. The women used the symbols of a sunrise, sunset, rainbows, and flowers and spoke about increased positive energies and purpose. Almost all of the participants (eight) took pictures of a sunset or a sunrise.

Marie shared her picture of the sunset and talked about having a renewed awareness of the beauty within life:

...I never ever looked at sunsets before but now I like to watch the sunset. I just find everything so...amazing...beautiful.



Marion talked about finding a picture of a rainbow in the winter time—something that is quite difficult to do. She similarly shared a renewed appreciation of the beauty of being alive:

Well... you're family, you're kids, and then when you go outside you appreciate so many things, like you appreciate ...trees... the snow, the grass, the birds... a rainbow like before it was just a rainbow, ...but now, after the cancer...to see a rainbow is another precious thing for me because it represents life...I'm alive to see this rainbow.



The pictures of sunsets and flowers were also symbolic of finding new beginnings and having a renewed sense of purpose. Sandra talks about her picture of the sunrise—symbolic of a new beginning and a chance to live again in a renewed way:

And then I took a picture of ...a sunrise. Just... because a new day had come. And that was it. You know, the day is starting and have a chance to, to live again, have a chance to make things better, have a chance today, to do some of the things that I wanted to do, and that's it.



Cancer not only offered a new appreciation of life, but the women talked about having a renewed chance to “become a better person” and to live according to their own priorities.

I want to experience more, feel more, I'm more accepting of everything. Like, you know when I say I've become a better person, I really have. (Sandra)

I was very humbled by their spoken appreciation for what really mattered to them. There was a spoken appreciation of *not sweating the small stuff* and focussing on their relationships, being kind and being a good person:

... because of cancer I have um, a new appreciation for life and...I am conscious of how I act or how I am with people. Cause my, my prayer everyday is that I will just be good and kind. You know, that I don't know, so that's important to me. It's important that people treat me like that. Like it's not, when I thought about treat others how you want to be treated and I thought no, no. No, no, just treat people good. You know. (Marion)

Living in the now and learning to *take time to smell the flowers* was important. Sandra shares:

You know, I don't think so much about tomorrow, I don't worry about RSP's at all. I don't have any. I don't care... It's very difficult to live in the now, but I mean I think that's where all of us are. (Sandra)

In describing her pictures of flowers, Cheryl explains:

There's my carnation. Take time to smell the flowers...so I kind of did that...that is an ongoing journey, but here I am, both feet on the ground ready to smell the roses.



In describing her new *appreciation of living*, Cheryl also talked about having a renewed sense of the importance of her body. Because she had lost movement in her arms throughout her cancer experience, she said that even *peeling potatoes* became exciting after surgery.

There is a growing body of research on resilience with cancer patients, which notes individuals' ability to thrive upon adversity and illness. The focus within this literature is on positive adaptations, which adds depth to understanding successful coping (Francis et al., 2008). This literature provides evidence of patients who are able to cope well with cancer and who even appear to psychologically gain strength from cancer treatment and survivorship (Mills and Dombeck, 2005). What the VBC adds to this literature on resiliency is the recognition that resilience is not an isolated quality, but is connected to personal qualities, relationships, social and cultural forces.

5.4 The Shifting Story: Personal, Relational and Social Factors Related to Resilience

Notable factors that the women attributed to their resilience included: 1) the importance of humour; 2) meaning and purpose; 3) strong personal histories and role models; 4) the importance of spirituality; and 5) support. Support is the topic of the next chapter. Other individual factors associated with resilience noted throughout this research were: maintaining balance between dependence on others and their independence; their sense of continued responsibility within their relationships and to their families; their ability to live with uncertainty; assertiveness and more.

5.4.1 The Importance of Humour

...with Aboriginal people, they tend to...use themselves...make fun of themselves... it's an easier way than having somebody else make fun of you, you know? (Sandra)

Many of the participants talked about laughter and its healing powers. Some of the women said that Aboriginal peoples use a lot of humour and making fun of themselves:

Like I love laughing and... you'll find with Aboriginal people, they tend to...use themselves and they make fun of themselves and it's more, it's an easier way than having somebody else make fun of you, you know? ...You know, I make fun of breasts all the time, but it's a way for me to accept and a way to let you know, it's okay...For

years, for generations, humour, making fun of ourselves or.... something that we've done. (Sandra)

Mary, Cheryl, Margaret, Sandra and Marjorie all talked about using humour as part of their healing. Mary said; *You cannot let cancer get you down, laughter releases tension and relaxes you.* Cheryl said; *...that is what I used to get through it too was a lot of humour.*

Cheryl took a picture of one of John Candy's movies to describe the power of humour.

Margaret similarly talked about how important it was to have a sense of humour because laughter she says is a *healing thing*:

*It's very important to have a sense of humour because, you heal, like for an example, if I was mad at....and all that and you come in and you say something funny. And I started laughing, it's healing, you make me forget that I was angry. *laughs**
(Margaret)

Using a combination of humour and positive thinking, Marjorie also describes her resilience:

I just refused to, you know, tell the doctors: "Oh God, poor me. I'm gonna die"...I'm spirited, I'm proud...to them I never amounted to a hill of beans but everybody has their purpose and...I'm here to live and learn and I've got a lot of things ahead of me...and if I don't look like your average little working whoever...like I have my part to do and I have my things to teach people... that's how I view myself...the package is a little scuffed up...but I am here...I am alive...

Humour was also used by friends and family. Cheryl talks about her friends wanting to do something for her after her surgery to which she replied, *I don't know...just hang a bra.* One of her friends decided they should hang the bras on Cheryl's chain link fence. When Cheryl returned from surgery there were twenty three bras there:

...twenty three bras, there were white ones, pink ones, green ones, blue ones, black ones. You name the size, I am sure they were there. And there was this huge bra that was hanging on my gate. It was just huge. So that was my support system the day of my surgery and it was fun.



I imagine Cheryl's friends were also reacting to her own ability to find humour and laughter even facing devastating illness, and responding in a way they knew she would appreciate.

All of the women either told me directly that laughter and humour were important to their healing journey, or they showed this to me repeatedly. I laughed with the women a lot more than I expected, especially talking about such a difficult topic. The idea that humour promotes wellness is iterated in clinical journals about cancer. For example, Christie and Moore (2005) argue that humour aids relaxation, anxiety, and discomfort, and is therefore used as a coping mechanism towards wellness. Christie et al. (2005) also suggests that humour has a positive effect on the immune system and may improve pain.

In addition to using humour, the women also maintained a strong sense of meaning and purpose, both throughout their words and their actions. These women had a strong sense of purpose which contributed to resiliency, at a personal, relational, political, and environmental level.

5.4.2 Meaning and Purpose

The ways that life meaning and purpose contributed to and demonstrated resilience were shown through many things, including; love, justice, family, teaching, counselling

and supporting others. The women's lives were filled with deep values and commitments, some enhanced because of their experience with cancer.

Meaning and purpose was also about a willingness to reach out to other women experiencing breast cancer. The women's willingness to share their stories and knowledge was strong within all of them and their commitment to helping family, community and beyond was humbling:

So, I just think you know the love I feel for my children is no different than the love you feel for yours...Not all of us can stand up and say stuff about cancer....or even admit that you have it, or had it. Those of us.... (Sandra)

The desire to help others was often presented with a strong sense of purpose. Sandra talks about questioning the purpose of her life after diagnoses, reinforcing that she wanted to make a difference:

I don't know, I think personally for myself, I mean, because you question what your life is about after being diagnosed....you know it's like "why am I here?, What am I supposed to do?" Or just feeling like you really want to do something.... So that when I do leave this place I will have done something. That's what I want to do.

Marjorie also talks about contributing and a sense of life purpose. I would add that she shows both humor and life purpose here:

*And for me like, I always think if I can, you know teach someone or make someone a little bit wiser in some roundabout indirect way, or direct way then hey you know... And I always say "well I'm gonna leave my mark on the world before I go" and I pray to God it was a good mark, not a bad one, you know? *laughs* So I figure oh well, you know one fine day maybe someone will, will appreciate what I had to say.*

This same sense of purpose was evident in my interviews with all of the women. Each of the women was participating in this study as a means of advocacy and was committed to raising awareness for Aboriginal women with breast cancer. Many women spoke of wanting to offer strength to other women.

The motivation for human beings to find meaning in their lives is often said to be most evident in the aftermath of traumatic events (Frankl, 1959/1963), including cancer diagnosis (Cordova et al., 1995). Several studies have demonstrated less distress for cancer patients with those who report more meaning in their lives (Lewis, 1989; cited in Jim et al., 2007). Literature here discusses spiritual, religious, relational, harmony, and many facets of meaning in life (Jim et al., 2007). This VBC research demonstrates strongly relational, individual and spiritual meanings relevant for the women during their cancer experiences.

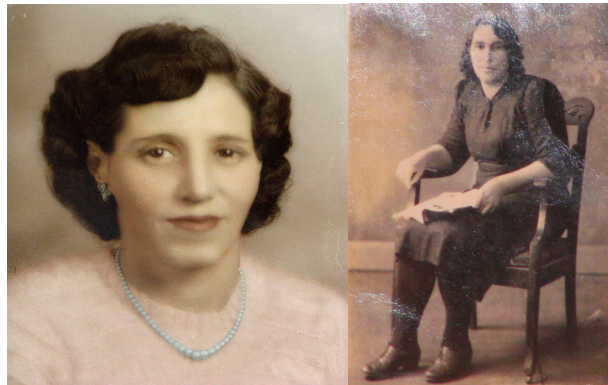
Symbolic of a similar theme, the women also spoke of people in their lives who contributed to their strength and resilience. This was attributed to positive and negative relationships and role models.

5.4.3 Strong Personal Histories and Role Models

I got a lot of beatings. I would fight back. I fought back against cancer too.

Many of the women talked about the really strong role models in their lives—often women who overcame many struggles of their own: Shelley talked about her two grandmothers:

...My little granny...she weighted about 86 pounds. I got a lot of wisdom, strength and learned to pray from her.



Shelley talks about how she watched her grandmother overcome struggles, always singing, happy and spiritual and how much of an impact that had on her life:

I just saw the struggles she's had, had to go through and how she overcame them and how she was always singing and how she was always happy and how she was, and I mean, for her, I mean she was, she was quite spiritual...And so, you know, I mean all the women in my life have you know, a fairly significant role I guess, and we're always strong and are always very positive and never, I never grew up thinking I couldn't do anything...Even though, I mean, dysfunctional family and they came from an alcoholic home, it never had that kind of a, like a negative impact on me. It was always, you can do whatever you want.

She makes the direct link between this strength and battling cancer:

And so, so when I, when I was sick or with cancer, when I found out I had cancer, I had never had a doubt that I could beat it cause I mean it never, had, I mean, it wasn't a thought, a thought that crossed my mind... I knew that, I had, a fighting chance because how I was raised by these women.

The women's strength also came from within—attributed to histories of living through violence with intimate partners and through residential school. Sandra said: *I always see women in my office get flowers. The only time I ever have seen my Aboriginal sisters get flowers is when they are dead.* The women have spoken about physical, emotional and sexual violence against them as children, within families, foster care homes and at day and residential schools: *I was raised in an incestuous home, abusive relationships...* And they have shared about intimate partner violence: *...police always asked—why did you go back and I would say it was safer knowing where he was.* Their words here are powerful and strong.

Violence against Aboriginal women from intimate partners and through residential schools are linked by many of the participants to the impact of colonization—and part of the complex web associated to wellness for women discussed above. The women's diverse experiences of spirituality are also tied to resilience and colonial histories. This is discussed again in Chapter 7.

5.4.4 The Importance of Spirituality

I found this rock... and on one side...looks like a breast...on the other side there is just a slash...and so...to me that's... for myself just having one breast. (Shelley)

There is argued to be a growing longing towards spirituality within society in general (Drouin, 2002) and a misunderstanding of spirituality as it relates to Aboriginal people (Zapf, 2005). Spirituality and traditional medicine for a number of the women was integral to self-identity, resilience and healing.

The women were not homogenous in understandings or expressions of spirituality. Sandra creatively outlines the tendency for mainstream society to make the assumption that all Aboriginal peoples follow certain cultural paths. She says:

...You know, I, I'm a person just like anybody else. I don't speak to animals and I don't know the answers to everything but, beads and feathers, yeah, beads and feathers are a good one for me... I'm not a beads and feathers person.

Marjorie's story shows how diverse religion and spiritual practices were even throughout her own experiences. She was a Catholic until she was eleven but she said that was ruined because of the residential school. Her family converted to Mormonism after that, which she said:

...hob knobbed with the First Nations belief...my grandfather was a devout Catholic...yet there was like gifted...elders in...our tribe and on our reserve there was like um really gifted elders that, you know, I guess in the here and now for political correctness, you call psychic ...and so like we got a taste of everything... And with the Catholic thing they pretty much wrecked us from the school, so when the Mormons came round, we converted to that.

Spirituality was also a positive means of coping for the women. But this meant different things for different women. A number of the women talked about the importance of prayer and Christianity in their lives. Cheryl offers her picture of candles and prayer beads to represent her faith.



Cheryl said that a lot of people would pray for her; ...*And I kept saying I am sure that God is tired of hearing my name.* She shares a story of her mother offering her holy water to drink, with her usual bit of humour:

She came the day before... my first chemo treatment with a thing of holy water, and she said, "I want you to drink this before your treatment". I said, "Okay". So the next morning I'm getting ready to go for my treatment and, "Oh yeah, I have to drink that holy water", so I poured it in the glass and I gulped it down. I went to my treatment and she called me and she said, "how did your treatment go?" And I said, "Oh, I'm better than I thought". I said, "I'm not feeling any different yet". And she said, "Did you drink the whole water?" And I said, "Yeah, I drank the whole thing". She goes, "What you drank the whole thing? I gave you enough to have a little sip for each treatment".

Cheryl's mother then went on a mission to find more holy water and she drank holy water for every chemotherapy treatment and before radiation treatment.

Marie similarly talked about Christian values. She describes her shrine that she had built and how important this was for her healing:

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.



Many of the other women spoke of strengths arising from the Aboriginal cultural, spiritual ceremonies and having faith in the Creator; “... they gave me the strength to deal with the disease and having faith in Creator”. Mary explains:

The Aboriginal Culture is very beautiful it brings the total nature, universe and the spiritual world together...Having that faith to heal and go on with my life and not to dwell on the disease.

Mary also talks about her mother’s very strong spiritual faith in God and the feeling of having her mother and grandfather from within the spiritual world right beside her through all of her treatment:

Even when I was going through the treatment, I could almost feel that she was right beside me all the time, so, that what helped me the most. I think that, that’s where the inner strength came from when, that support that I got from my mom. My grandfather also appeared once in a while. I would dream about him, telling me that everything was going to be all right, not to worry. So, from the spiritual world I was getting all these messages, that everything was going to be fine, not to worry, to go through this, and everything would be fine.

Mary also attributed her strength to the symbolic angel, which she said gave her peace of mind and courage:

The angel brings peace of mind it and gives me the courage to go on when I was feeling really sick. That picture of Jesus too is right by my bed too. I always keep it beside me. Because I know that he’s there with me when I need him.



Shelley talks about changing the serenity prayer to fit with her Aboriginal spirituality:

This..[serenity] Prayer...I've change...to fit into my Aboriginal culture...Instead of saying: God grant me the serenity... I say... Creator, Grandfathers, Grandmothers... Spirits...give me the peace of mind, that I need to accept person's, place, situations exactly how they are.



Strength also came from personal identities that were very much linked to Aboriginal spirituality and traditional culture. Shelley explains the importance her sash and her drum and how each of the colors in her sash are representative of identity—blue, represents her Métis history and is west, white is north and represents snow, water and spirituality. Her colors represent her healing journey and her medicine wheel. She explains *...even with my drum, those are my, again, my colours...the drum and my sash are quite a big part of my spirituality.* She further explains the significance of the drum in Aboriginal culture:

And I mean the drum, I mean drum is, 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...



This also draws attention to the importance of rocks and other symbols of Aboriginal culture. There was also comfort taken in the symbols of Aboriginal culture.

The symbols that you call are our ancestors, the animal spirits and the four elements, colors and directions. The eagles are the grandfathers or messengers that take the prayers up to the Creator. The Aboriginal culture is very beautiful...it brings together the total nature, universe and the spiritual world...

Four women spoke about the importance of the Eagles. Marion found a picture of an Eagle to include and shares what this represented during her illness:

...in the Native culture...the Eagle is a really...sacred bird. I always feel blessed when I see an eagle and I always know that I'm gonna be here for awhile. I'm gonna be all right.

Mary explains how sweet-grass and smudging helped her keep focussed and balanced:

There are time when fear will set in, and those times I used my sweet-grass and smudged myself and prayed...



Rocks and nature were important in healing. Mary explains that she has many rocks in her apartment and how they are used in sweat lodges:

...The rocks are very important in my life and they are used in the sweat lodge. When we go into the sweat lodge we, 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. They give you energy as well.

There seems to be a renewed interest about spirituality within helping professions and a number of disciplines, including critical social work literatures and sociology. A recurrent theme in spirituality research within the oncology social work literature, for example, is that understanding spiritual dimensions in healing also helps to create more meaningful helping methods (Coholic, 2005). This has been attributed to a longing for meaningful and more profound connections to ourselves, others and something greater, because of flourishing materialism, individualism and the ruin of community and environment (Drouin, 2002). Spirituality is now emerging in a number of disciplines as a significant area of scholarship—making the input of marginalized knowledge even more important.

These findings also iterate the importance of the connection of spirituality to the real environment—trees, rocks, earth, fire, moons, sun, air and water were very much associated with spirituality and identity. This is lost in much of the mainstream helping literature. Zapf (2005) for example argues that perspectives within the mainstream urban social work and spirituality literature seem to carry constraining assumptions which dangerously may omit the environment and the relationship of the person to the environment:

Just as we limited our understanding of environment to only the social environment, I am concerned that we may also inadvertently be limiting our understanding of the broad concept of spirituality to simply a component of the individual person... We could be missing a broad and exciting concept that holds the potential to expand our understanding of the professional's foundation person/environmental relationship (Zapf, 2005: 1).

For a number of the women in this study, spirituality and traditional medicine was integral to self-identity and healing. Participants were not homogenous in understandings or expressions of spirituality and emphasized that it is important to acknowledge that diversity—as with understandings of spirituality among any cultural group (Zapf, 2005). The assumption of sameness, led to alienation and Othering, expressed by the women as part of their experiences of discrimination based on race. This is discussed at length in literature on dangers of incorporating culturalization into health policy reform, developed in Chapter 7.

5.5 Synthesis

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 which evolved shows the importance of the social context on survivorship experiences—both psychological and physical experiences. The model of understanding that is developed shows how fear, anger and feelings of helplessness/being out of control were 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; race and racism. Our findings highlight the need for policies/health care practices and research (including research in socio-oncology, psychology, epidemiology, medicine, sociology and more) to identify survivorship in the

complexity of lived experience, contextualized by interconnections of race, class and gender.

Resilience was associated with spirituality, environment, traditional medicines, history, life meaning, laughter and more—also connected to the larger context of culture, race, class and gendered experiences. The women spoke of their strength and resilience as connected to: being strong women; having strong women role models; important teachers and support in their lives; struggles against violence and residential schools, dysfunctional families, as well as being influenced by spirituality and traditional teachings.

The women's stories then reinforce a number of themes within the epidemiological and sociological literature on the effects of socio-economics, gender and racial factors. Their own stories were more reflective of systematic barriers; such as financial difficulties, not being able to leave work places easily, difficulty with finding transportation, lack of relevant information, lack of relevant support (both financial and psychological—discussed in the following chapter), experiences of racism and stigmatization; and their responsibilities for care of families, financially and otherwise. These systemic barriers point to the notable interconnection between racial and socio-economic barriers for the women. I 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, racial and class inequalities. I suggest that if health professionals are made aware of the repercussions of these experiences that they may become part of a solution to increasing quality of life and survival rates for Aboriginal women.

The women's pictures and words show the importance of beginning with the perspectives of marginalized people towards deconstructing social constructions of race,

culture and Other. Yet, they warn how making assumptions about class, culture or racialized identities disenfranchises Aboriginal women further. Although the women want to ensure that the stories of the most disenfranchised and isolated women are heard and seen, this research cannot gloss over heterogeneity. The women know we cannot essentialize their identity based on the most underprivileged, yet we also cannot gloss over marginalization nor racism. I argue, that we must be able to talk about the very real social problems the women, while focussing on heterogeneity, resiliency and the link between social problems to roots of colonialism. In fact, if we are only sensitive to specific needs or cultural differences without viewing an individual within their social location as related to colonial marginalization, we may reinforce institutional discrimination.

In conclusion, the women situated their everyday lives, including experiences of racism, violence, employment histories, socio-economic realities, relationships, silence and anger within the continued effects of colonialism and systemic racism. They defined their own and others health needs as well as resiliency and strength in this very complex way, talking about the intergenerational impact of residential schools, loss of culture, impact of foster care homes, violence against them. They spoke of silence and anger, alcohol and drugs and violence in a way conscious of the link to historical oppression and continued racism. This level of analysis was also evident in their discussions of support, the topic of my next chapter.

**Chapter 6“For the first time in like seventy-five frickin years the
woman checked her breast”¹²
Visualizing Culturally Appropriate Social Support**

Although there are many studies which reveal the social support networks of breast cancer survivors (Stansfeld et al., 1997; Wilkinson, 2006; Mansyur, Amick, Harrist and Franzini, 2007), there is less research which reveals how historical, cultural and racial experiences may impact sources of support for Aboriginal women. This chapter explores sources of support for Aboriginal women ‘through their eyes’. The findings reveal social support as context dependent and reinforce the importance of understanding the intersection of class, ethnicity and race. The emerging framework reveals four noticeable social forces, namely: a) race and racism; b) geographical space (rural, urban, on reserve); c) historical and cultural experiences of Aboriginal women; and d) socio-economic situations that affect women’s ability to secure/garner safe social support and adjust to her role as a cancer survivor. My findings highlight the importance of drawing on anti-oppressive and feminist theory to understand Aboriginal women’s experience of social support. The information gathered provides an entry point to make visible often marginalized knowledge about: 1) existing support systems; 2) the effect of class, gender and race.

¹² Sandra

6.1 Existing Support Systems

My family, my children, grandchildren, friends, Elders and healers...were all support people. (Mary)

Social support is defined as something received, whether tangible (such as financial assistance) or intangible (such as reassurance), and has been linked to well-being amongst breast cancer survivors (Shaw et al., 2000; Lugton, 2008). During times of crisis, people are said to need the assurance and love of those who are the closest to them for support, security and for their self-esteem (Lugton, 2008). In literature about breast cancer, social support is tied to allowing people to maintain their identities and successfully navigate changes and adjust to changing circumstances (Lugton, 2008). The VBC interviews concur with this medical and nursing literature and iterated the importance of loving, emotional support, practical help, companionship and confiding. The findings also illustrate specific support needs, such as support for physical changes and finding other women who have successfully recovered.

6.1.1 Just Being There: Positive Support from Families

The women's pictures in the VBC research were filled with husbands, life-partners, children, foster children, grandchildren, step-children, friends, parents, grandparents, siblings, cousins, Elders, traditional healers, spiritual friends/leaders and community members. The women spoke of tangible and intangible support and the importance of their families. They also, however, spoke about family members not being enough and conflicting needs to support their families. Following is a snapshot of the

women's perceptions of the importance of their families. I begin with Mary, who summarizes the importance of family, Elders, spirituality and traditional healers:

My family, my children, grandchildren, friends, Elders and healers and the medical people were all support people. Most importantly my traditional friends and the ceremonies and healing medicines helped me heal emotionally, mentally, spiritually and physically.

Husbands, life partners and families contributed to tangible and intangible emotional support. Many of the women said their husbands went to every doctor's appointment, chemo treatment and/or radiation treatment. Marion said her husband sat beside her bed and took her everywhere she had to go:

...when I... went through my surgeries he sat beside my bed, like the whole day, he'd cry. And, every chemo treatment he took me, he, he wouldn't want... anybody else to take me.



Tina similarly said her husband never missed appointments and sat right through her chemotherapy and radiation treatments:

... he was so, everything, I, he never left my side, ever. He allowed me to cry. He allowed me that time to recover.

Tina talked about her husband feeding her, especially when they told her that her red blood count was low. When doctors showed her that her count went below a certain number that they were going to have to adjust the chemotherapy to take time to rebuild her body, her husband responded immediately by feeding her a lot of red meat every day, and pumping her with vegetables and juicing. She remembers:

At the end of my chemo, my blood count was a hundred and nineteen, which is one point off ...normal. So they told me that I have actually improved through the process... Um, but then I have the side effect of, my bloods are going up because of all the red meat.

Many of the women talked about the (often hidden) emotions and fears of their partners. Tina, for example, recounts that her husband made himself strong, hid his emotions and cried by himself. He thought if he broke down that she may not make it through everything:

...he wanted to make sure that he was doing whatever he could to rebuild me and keep our family going...So he just made himself be strong and he hid his emotions and he said he used to cry by himself. I remember waking up in the hospital and he was sitting by my bed and he was, when I woke up, he was just crying and, as soon as he knew I was awake, he just quit it.

The women also talked about their children bringing joy and healing. Women spoke of wanting to get better to watch their children grow and they spoke of the emotional support and feelings expressed by their children. Marjorie said:

If I've ever needed something to live for and a reason to be alive...well there he is, you know.

All of the women told me that their love of their families was key to survival. Marion similarly shares:

I always prayed, to live, to see my children grow up...to see them graduate, to see them get married and be off on their own...I thought if I am gone...they will never have another mother...to love them the way I do.

Tina talked about how her children would crawl into bed with her and hold her. Her daughters would crawl right in and her son would lay at the foot of her bed. She also talked about their fear and concerns:

...he just looked at me and he ran and he ran and he ran....my one said...I didn't have a dad...you were my mom and my dad... as young as I am, um, he says I got things that I have to worry about, no... I got to worry about my mom.

Mary said babies were *part of my healing process*. Children, she said, bring *so much joy*.



The women said that they did not need reassurance and their families did not need to say the *right thing*. The fact that they loved someone so dearly made them want to get healthier—especially for their children and little grandchildren. Sandra links her love for her children to love for all children:

The love I feel for my children is no different than the love you feel for yours.

Children, foster children and grandchildren also provided their support for the women in a number of diverse ways, including praying, understanding, reassuring and showing their love and caring. Marion talks about receiving love from her foster child and how important that was to her healing:

this one is ...my foster child. I had him for three years and...he's a really great kid. ...He knows that I had cancer and he always prays for me and, he's always beside me, like I go for walks everyday and he's always there with me. He always wants to be next to me and, he always prays for me and, he's just a great kid, I just, I really love him.



Cheryl talks about a *barf pail* that her granddaughter made for her. She said this is a picture of *children's love*. She was only seven years old, yet Cheryl remembers; *she understood what I was going through.*



Many of the women talked about care-giving also coming from their children. Mary remembers the support of her daughter throughout her illness:

She lived in Saskatoon...when I was really sick and... she came and made food for me or brought food over for me and just helped me a lot. And it's just, being under the tree, it's ...nice to have a picture like that.



Like many of the themes presented, I can not possibly include all of their words or pictures, but I wish I could. The women took more than 50 pictures of their families. I have therefore included the photovoice poster, entitled: “The Importance of Families”, appended at the back of this dissertation (along with the other three photovoice posters created towards research dissemination). I conclude my discussion of family with Marjorie’s picture of her family here:



Although the women talked extensively about the positive support concerning families, many women also felt their families could not understand the realities of the illness and of the physical changes. As a result, they often felt that they had *no support*. Social support is also said to be necessary to help cancer survivors feel less threatened and overwhelmed by their diagnoses and experience (Lugton, 2008). Part of this for the women was the need to restore their identities as healthy people. Many of the participants felt that social support meant finding other women who had successfully gone through breast cancer.

6.1.2 *He didn't have a clue: Needing Someone who has Been There*

The women expressed wanting to talk to someone that had gone through breast cancer, who could also understand the realities of the illness and the physical changes. Tina expresses her distress at not having had this type of support, even though her partner was present for all treatment:

So you know, on one side, I put my body to sleep...I really depressed myself and I hurt myself even more so. And it's because I didn't have no support. None. I had no one to talk to... how do I talk to my husband about that? He didn't have a clue. Other than, you're not dying. And my children, you know, "Mom are you dying?..."

Cheryl desired strongly to talk to someone else that has been through cancer and survived. She appreciated the love and care of friends and family, yet felt that they were often even afraid to hear the word "cancer", which deepened her fear:

They don't want to talk about it. And they don't want to talk about how you feel sometimes. They're scared.

Similarly, Marion talks about how her family tried, but could not possibly understand because they had not gone through it:

Yeah, like my husband or, or my sisters or whatever, like I don't talk to them because I feel, like, well they don't understand. They don't know, how, what it is like, or... how it feels to live in fear all the time because they haven't been through it.

Marion said that she had *no-one to talk to*. Her story speaks to the importance of two kinds of relationships and support—the support from her husband and family as well as her need to talk to someone about her relationship and physical changes.

What if people laugh at me? And I went, I went for my surgery and I prayed a lot. I went through it like strong. By the time I came out of my surgery I accepted the fact that I lost a breast...there's a lot of things I couldn't talk to anybody about. Even the lady that I talked to... I couldn't tell her... well I'm ashamed and I'm afraid my husband is gonna leave me, I'm afraid people are gonna laugh at me and... I'm afraid my husband is gonna think I'm ugly, or you know...

Similarly, another participant talked about feeling that she had no one to help her with her decision about whether to have breast reconstruction:

...because mine was very close to the nipple they said that they'd probably couldn't save the nipple, and, so I thought...what would it like, be to have a boob, with no nipple? That would be so odd. And, you know, I mean because I'm still young and I, and I still get intimate with my husband. How is he gonna feel towards it and I had no one to talk to about that... (Tina)

Many of the participants spoke of their concerns regarding physical changes and how this shaped certain needs around support and relationships.

6.1.3 Support for Concerns with Physical Changes

The participants also talked about their support needs associated with the physical changes. For some of the women the physical changes were so devastating that they thought of not undergoing the treatments or would not leave their home when physical side affects began to appear. These women talked a lot about the authentic support they received from their families to help them through this.

Tina, for example, describes herself as an emotional wreck because of her weight gain and because her hair was gone. She took a number of pictures of herself and talked about how much cancer changed her appearance. She talked about never wanting to leave her home and that her husband did everything for her:

But I was such an emotional wreck because my hair was gone, I was now wearing a wig. I never went out of the home. He did everything, he was my eyes, he was my mouth, he did everything.



The impacts of physical changes were often very devastating and the support of their partners was important. One participant talked about the discomfort she had being intimate with her partner after breast cancer, and being able to take off her shirt:

...as for intimacy... you have to relearn. You're, you have to teach your husband that, there are other places you know, foreplay has, it looks different than it did before...you can't go right for my breasts. I mean he doesn't touch them, we haven't got to a point yet and it's been five years, so, where I don't feel, completely comfortable, I don't think we've made love without my shirt on or something, you know... not because of him, but because of me. (Sandra)

She said she feels lucky that she is married, because she is certain that she would not be able to become intimate with anyone else. She said her husband knows all her scars.

There was also fear about losing relationships and feelings of isolation for some of the women associated with the physical changes. Marion initially had a lumpectomy because she could not stand the thought of losing her breasts. The doctor, however, could not guarantee that this was enough so she had her breast removed. Marion talks about her fear and her shame related to physical changes and her relationship with her husband.

When I went through that it was really hard because I was um, I was afraid, I was afraid my husband was going to leave me....I was afraid like, what are people going to think of me? You know? Except that I didn't know that, how I'm moping around like and, I was so ashamed, you know? I was really ashamed and I was afraid, actually all I was afraid of, was what if my husband?

Humour was used around breasts and prosthetics within their relationships quite a bit. Marjorie, for example said: *and...[I would] spin a sling and throw it....* Sandra, both with humour and sentiment talks about throwing a party for her breasts:

I missed my breasts. I wanted to, to thank them, and to, which is why I had a party for my breasts. Because I nursed my children, and you know my, my husband made love to me and you know, your breasts play a big part in all of that. It was just the body image and missing that piece of me.

She used a picture of her friend's cleavage to talk about her story with humour and laughter:

This is cleavage, which looks like bum. I got my girlfriend to pull her shirt down so I could take picture of cleavage, just because, I missed it, you know...



Most of the respondents talked about needing some support to cope with physical changes of losing their breast, and this seemed to be quite tied in to their sexual and feminine identities, and their comfort in their presentation to intimate partners and others. Whereas other studies have suggested that support to cope was available for their participants (see, for example, Lugton, 2008), many of the VBC participants coped quite silently.

Two of the women also expressed grave fear around losing their hair. Marion said that losing her hair was the hardest part and brought on suicidal thoughts. Although she felt that no one could understand, this story is also one of her sister's and sister in law's showing memorable support. She expresses how hard losing her hair was for her:

And, the hardest part for me was when I was losing my hair... when my hair was falling so bad I, I just one night I woke up at two o'clock... I went in the bathroom and I cried and cried and I got the shaver and I shaved my head ...every time I touch it, it was on fire, and it was the hardest thing for me to do and I just like, it was really hard like at that time. When I was doing that I never told anybody but, I had such strong thoughts of suicide. I just wanted to um, get it over with and kill myself because I figured ... I just couldn't do it.

Marion talked about not going through with her treatment initially because of her fear around her hair. Her sisters all gathered together and cut their own hair as a sign of support.

The picture below shows Marion cutting her sister's long braid.

When I first started losing my hair, I wanted to quit chemo it took a lot of encouraging from my family ...My sisters had long hair, and this was a great sacrifice for them, like to cut their hair.



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: *...when I lost my hair, I cried. I cried. Well now, maybe I'm gonna die....* She cut her long (never been cut) hair into a long braid and brought the braid back home to her husband:



Being an Aboriginal woman, the importance of cultural healing and the impact of physical changes was something that many of the women talked about not feeling comfortable

sharing with non-Aboriginal people or support groups—which I discuss more fully in the following section.

Support needs surrounding physical changes showed up quite differently for two of the participants. These women felt that their own physical identities were not threatened because of the physical changes, rather because of the reactions of others to these changes. Cheryl was frustrated at other people's assumptions about the physical side effects of treatment for breast cancer. Part of her frustration was that people would focus on what she saw as the temporary and more irrelevant aspects of breast cancer:

...that's the first thing everyone relates chemo to is losing your hair. And it was more than losing my hair there's more side effects than losing your hair. Losing your hair is peanuts... [my hair] is going to grow back, my bones aren't going to be the same when I'm done with this, I know that. You know, let's concentrate on the other things that are going to live with you longer...

Cheryl talks about people focussing on the loss of your breast or losing your hair, which to her was not as important as *chemo-head* and the fact that she could not *multi-task* anymore...*I can't concentrate or I can't do two or three things at a time...like I used to remember everything, so it is frustrating.*

Sandra talked about other people's discomfort with their physical changes and the things that she would do to help other people feel better. Showing a picture of her daughters covering their faces with hats and scarves Sandra talked about how she used

wigs and prosthetics to make others more comfortable:

People couldn't stand to see me bald so I'd wear a hat for them, not for me....



I find it interesting that she is not showing their faces—symbolic perhaps of losing some identity in hiding her bald head and what she was actually going through. Breast cancer was talked about as being quite threatening to physical identities, and the women linked this to the importance of their intimate partner relationships, support, humour, masking and camaraderie.

The women needed a sense of belonging and they all spoke of desiring a sense of fellowship with other breast cancer survivors. Fellowship seemed to decrease their sense of isolation. However, feeling that other women had found that camaraderie and that they were slighted because of their race increased feelings of isolation and seemed to threaten their identities. As in Chapter 5, the story begins to shift to include the combined effects of race, gender and class.

6.2 The Story Shifts: The Effect of Class, Race and Gender

The story shifts here to include the social context of the women's lives—and the influence of socio-cultural, racial and other social forces. I begin with 1) a brief description of how important finding another Aboriginal woman with breast cancer was to almost all of the participants. Many of the women disclosed a connection between being an Aboriginal woman and the ways that this changes support needs. I demonstrate this through their description of 2) norms associated to being an Aboriginal woman and what this means regarding caring for others; 3) the importance of traditional healing and spirituality; 4) living on reserve and cultural norms of silence; and 5) wanting to support others.

6.2.1 Wanting to Find Another Aboriginal Woman: Problems with Support Groups

You know, most Indian women feel more comfortable with other Indian women and open up to their concerns and issues (Mary).

Most of the women agreed that they did not have the opportunity to talk to another Aboriginal woman with breast cancer. All but two of the participants recounted that they had not found another Aboriginal women throughout their breast cancer treatments.

Sandra, a VBC participant, who is also on the board for Breast Cancer Action

Saskatchewan, said that out of all of the events on breast cancer that she attends she has never seen another Aboriginal woman survivor:

I always looked for somebody like me, like an Aboriginal person when I went in there. So anytime I saw somebody that I thought was like me, I would look at them and, you know, try and make eye contact right, try to say hi or talk to them or something.

Tina similarly remembers talking with her doctor about never seeing another Aboriginal face. She recounts:

I said, you know, when I first went through this, I looked around for any...I could find out there. And I said I couldn't find any like me out there. She goes well, Tina there's a lot of you. I said really?

All but one of the participants stated that finding another Aboriginal woman to talk to was eminently important to her and felt uncomfortable in support groups where they were the only Aboriginal person. Tina says:

I wished...I would still love to talk to a Native woman...because I still live with fear... I would have loved to see another brown face in there, not that I'm racist or anything like that, I just needed to see another....

Marion recalls another woman on the reserve who was diagnosed and she does not want to talk to anyone from the cancer society. She says it is easier to talk to another Aboriginal person. She states:

And I can see that now...how easy it is...to talk to another Native person... And, and it's easy for her to talk to me and it's easy for me to talk to her...and, I find it so easy to talk to Native women, compared to like, when, I was going through it I had such a hard... talking to __ [her non-Aboriginal support volunteer].

Reasons they gave for discomfort in mainstream support groups were individual, cultural and political (about racism). Most of the women said they just did not feel comfortable. Marion shares:

And, and sometimes I just don't feel comfortable...like a few of the ladies always try their best to make me feel welcome and that... But there are times I just don't feel comfortable and I always want to try to make a support group like on our reserve like, like for, for cancer patients, but I never knew how to go about it.

Sandra also talks about not feeling welcome in the support groups and not feeling like her volunteer services were welcome:

...they did have support groups but the one that I did go to was old ladies, old white ladies, who had cancer ...I just didn't, I didn't feel comfortable in going back and I didn't feel welcomed and a lot of times I tried to volunteer my services too and... they'll take your name but they never phone you or anything.

Three of the women said that they did not even try to become a part of the groups around the clinic or hospitals, because of their experiences when they did try to be part of the group, and because they assumed that they would not fit:

I didn't look around the walls of the clinic or the hospital when I was there. I, I didn't take part in look good, feel better anything. I just, I think because of my history and...(Sandra)

Cultural differences, in class and race, were also seen as barriers to participating in support groups or having positive interactions with health care providers or support workers and volunteers. The women felt support groups were organized around the dominant culture. Some women explained that it was difficult to talk to non-Aboriginal woman about their cultural background because they would not understand. She said that this interferes with successfully being part of a group or support network:

I never even, told her about the cultural part like what I did, like, through the Indian way and all that. But, I explained to her about, my praying and everything because like, there's some things that she just wouldn't understand. (Marion)

The participants linked the reality of their lives to other Aboriginal women's experiences and talked about shared concerns not appreciated or able to be addressed by the support groups they attended.

Support needs were complicated by their own roles, which were often defined by supporting others; their families and extended families. Many of the participants found it

very difficult to ask for support and coped by continuing their role of supporting others and hiding their own needs.

6.2.1 Self-Care and Caring for Others: Lord please... let me keep my job so I can feed my children (Sandra)

A few participants emphasized that many Aboriginal women have raise children by themselves, or run their home by themselves and this affects how you can be sick:

...if you are all that the family has, then you're holding up a lot of people and you can't afford to be sick.

These concerns were practical and financial and weighed heavily on their experiences of survivorship.

The women also suggested that these responsibilities for their families were part of how they were raised as Aboriginal women.

This is who we are...this is what we do. You know its like...its our worth...we're raised or culturalized or whatever to ...be this type of person...we have these jobs as a woman to do. (Sandra)

The women expressed that they are the ones that do the cooking, the cleaning, the parenting, the disciplining, the budgeting...

...you do everything, you know...the worrying, the everything...like with my ex-husband, he would do the drinking. I mean that was how he dealt with things. You know? ...You can't let yourself be sick...I don't have time for this lump right now... I'm just gonna like not think about it. (Sandra)

Financial concerns also weigh heavily. Sandra shares that she often feels 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, 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 sometimes...



The care-giving roles were said to influence the women's ability for self-care. This also meant that many of the women had to find ways to cope with not being able to do their own daily roles—such as being there for their family's well-being, supporting them financially, practically and emotionally. Sandra says she became *supermom... superhuman* and did not give herself any time and tried not to upset anyone. She said that she would cry in the bathroom with the water running. This is expressed in her picture of masks (below)—the masks she used *for other people* and to hide her pain:

Yeah, I did. Um, I tried to hide everything from them. You know, I tried to do everything...yeah, I don't know and for my family there was the one consistent mask. And the only person that ever saw the pain was me.



Other participants also expressed hiding in the bathroom to cry, especially when they were first diagnosed—because they did not want to upset their families. Marion talks about her eleven year old who was so young he could not understand what was happening and was scared. She said he would cry a lot and that was one of the reasons why she would hide her own tears. Throughout her experience, she also explains that her children learned a lot about cancer:

...that's why, that was one of the reasons why, I started going into the bathroom and not letting anybody see me cry because I was, he was really um, scared...And now, today like, he, he knows so much about cancer.

A number of the women came up with ways to hide their pain and cancer experiences from their families while they continued doing everything. While research on gendered roles of care-giving and self-care have emphasized cancer diagnoses as changing identities and women finding a “balancing act”, establishing boundaries, accepting and asking for help (Sulik, 2007), many of the VBC women became *superhuman*, hid their pain and continued doing everything. The women talked about this being a norm within Aboriginal families. Although this cannot be generalized to the diverse Aboriginal population, I argue that this suggests that the ways in which women negotiated care work must include a discussion of the influence of race and family history and norms. I argue further that inordinately high levels of family violence amongst Aboriginal families (Statistics Canada 2005) are one of the legacies of colonialism (Comack, 2006) which means that women’s self-care norms must also be understood in this historic context.

The refutation of traditional healing knowledge and practice is also part of the legacy of colonialism, including residential schools and government policies of assimilation which included outlawing ceremonies which were healing directed (Waldram

et al., 2006). The women's stories of support networks include Aboriginal and alternative healing methods as we saw in their description of family support. Traditional practices are important to note here for three reasons: first, because their support networks include family members who were healers and offered this support to the women; second, because a few of the women found support and healing within these traditional practices and ceremonies; and third, because the women who used traditional and Aboriginal healing felt that it was important to hide this from mainstream practitioners and health care support groups and individuals.

6.2.2 The Importance of Traditional Medicine

Women who practiced traditional methods of healing were not forthcoming to practitioners. They assumed that there would be stigma against them. As discussed in Chapter 5 and in the earlier discussion of the importance of families, the women talked about the healing nature of Aboriginal cultural ceremonies, such as the sweat lodge and Sundance; traditional and healing medicine; importance of spirituality and nature; and other forms of alternative healing.

The importance of these forms of healing and ceremonies, as support, also seemed to be involvement in something that was safe, positive, natural and free of racism. Shelley explains that everything within the sweat lodge is safe, everything and everyone is equal when the door is closed:

There's no racism in there, there's no nothing in there...It's really like a positive experience.

Four women spoke of family members who contributed to their healing directly because they were healers or they had knowledge of traditional medicines and alternative healing techniques themselves. Two of the women also spoke of their husband's role

within their communities as healers and how they supported their healing. Dorothy said her husband makes people laugh and is gifted. When she lost her hair she gave the long braid to her husband, as mentioned earlier. Her husband took the braid and he smudged it and reassured her that her hair would come back:

*...and I told my [husband] when I got home...I give it to my husband. He smudged it, and he...he prayed, that your hair will come back. ...And, he said that... I'm gonna look like, Crazy Horse *laughs*...He always makes people laugh.*



Mary attributes her brother with taking the cancer out of her body:

...having faith in the healers that came to my life and the medicines they gave me. Their medicines were very strong and helpful in my psychological and physical healing. When my brother worked on me I knew that he had taken the cancer out, I felt it leave my breast.

Margaret explained that her husband had a dream about her mother who said that she was going to cure her of cancer. He said that he would drive her up there. Her mom doctored her and she said the cancer was gone:

She told me what she used. My dad told me, he said she was gifted, she dreamt about it.... and I... took that medicine... drink it in the morning... the next day, when the x-rays were taken, they asked me what did you do? He [the doctor said] there's nothing here. We can't see anything.

Having faith in healers and traditional medicines was also said to help in both physical and mental healing.

All of the women who practiced traditional methods of healing and found spirituality important in their healing journey said that they either didn't share this part of their experience with health professionals or felt that it was not responded to favourably.

I didn't think that they [doctor's] received it very well and probably tell me not to go to faith healers and the Indian medicine would not work because it hasn't been scientifically tested.

There was a strong feeling that health care professionals do not believe in alternative healing methods, so most of the women "just didn't bother" to inform them.

Most Doctor's don't believe in alternative healing... the Aboriginal culture is very sacred and therefore most of the medicines and healing techniques are passed down to relatives or those who are very gifted. And so I just didn't bother telling anybody what I was doing.

Part of this seemed to be in fear that the doctors would tell the women that they should not go:

I didn't even tell them I went to sweat lodges or anything like that, 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, and of course getting my brothers to work on me and going to the Sweat Lodges and healing ceremonies.

The women assumed that their behaviours, which they defined as outside of the mainstream mentality would be judged. Margaret said that she was *told not to say anything* and quite enjoyed seeing how shocked doctors were at unexplained improvement:

The next day when the x-rays were taken, they [the doctor's] asked me, "what did you do"? He said, "there's nothing here. We can't see anything". And uh, of course I was told not to say anything. So I didn't tell him, I said "I don't know". "What did you drink, what did you eat"? And I wouldn't tell him, what I drank, and that. So they couldn't see anything, so it was okay...there was nothing there, they couldn't see anything, they gave me x-rays, one to another x-rays and they couldn't find anything they were surprised they were shocked.

Themes from literature on the refutation of traditional health models and misunderstanding of Aboriginal people's experiences of spirituality (Frideres, 2009) are reflected in my findings. Frideres (2009) argues that many First Nations peoples have an understanding of healing, spirituality and medicine whereby objective, rational, emotive scientific presence is foreign. The women who practiced traditional methods of healing were not forthcoming to practitioners—assuming, as Frideres (2009) articulates, that there would be bias against them. The participants assumed alternative medicine and spiritual teachings would be judged by mainstream practitioners. Waegemakers Schiff (2006) argues that recognition of the importance of traditional healing practices of Native peoples has accelerated a reversal of the historic efforts to eradicate native traditions and created an upsurge of interest in traditional healing practices including the Sweat Lodge ceremony.” Frideres (1994; 2009) argues that many Aboriginal patients may heal themselves and not follow specific medical orders and as a result risk being labelled “irresponsible” or “incapable”. The perception of the relationship between alternative medicine, traditional forms of oncology by both doctors and patients would be an important topic for future study.

Understanding the larger problems of colonization meant for most of the participants that their stories extended from themselves to other Aboriginal women—

especially those in more remote and isolated communities and on the reserves in Saskatchewan. They wanted to find a way to reach isolated and silenced women, who may not receive screening or early detection and may not complete their treatments.

6.2.3 On Reserve Living and Political Outcries

We need to tell each other its okay to take your shirt off, so what if you are lopsided, you are alive...but we have been hushed...

Concerns regarding support for women living on reserve followed two interconnected themes addressed here. First, the condition on the reserves and in isolated communities was less than ideal for early detection and screening or for healing from breast cancer. Second, the impact of cultural norms and beliefs about bodies, health and cancer affected women's 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:

I think 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.

She talks about a woman that used to phone her:

I don't know, I don't know if she's still alive but she had breast cancer too, and, she went to a couple of treatments but she's was drinking and I don't, I don't know if she, continued. I have never heard from her again. And I don't see her around. I hope she survived.

Sandra spoke of a woman whose cancer became visible on the outside of her body, yet 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?

Lifestyle and problems with drugs and alcohol were linked to avoidance for some women on the 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, 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. But I, I talked to her and, and but she doesn't talk about her breast cancer...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.

Sandra talks about her experience and her shock at an Elder who had never checked her breast in seventy-five years:

I just kind of asked them sitting around, you know would you be interested in this, like an afternoon session on breast cancer or, and a lot, lot of interest. Really great 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.

Many of the women discussed stigmatizing beliefs about cancer by members of their families or communities especially when they were from a reserve community. This included beliefs such as *if you touched yourself you invite the cancer into your body*. (Marjorie) Other beliefs were that *cancer is very contagious* and that *people always die from cancer*. (Marion) The women shared stories of family members who could not look at them or talk to them while they were going through cancer. An Elder told me to remember that many Aboriginal people feel that they cannot acknowledge a lump: *When I found my lump... I didn't want to invite it*.

Similarly, Sandra talked about people that she knows who have refused to go to doctors when they have found lumps. She said that was either because they did not want to hear they had cancer or they felt that if they were not told then it would not be. She said she felt similarly when she found her lump:

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

Another participant spoke of some cultures which 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?*:

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

A few participants discussed 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 those women who are living in more isolated communities and the impact of reserve living.

The participants discussed strategies that were important to more effectively help women living on reserve than the existing strategies. They wanted to be part of finding a solution. I close this chapter with the women showing strong desire to help other women, on reserve women, rural, and urban women.

6.2.4 Wanting to Support Others

I want [other women] to feel that they are not alone...other people...care about their illness. I want to pass this along to them.

Although it was also difficult for many of the participants in this study to speak out, they all agreed that they could not avoid thoughts about cancer and felt that they wanted to make a difference to other Aboriginal women (for one participant, other women generally) with breast cancer. Showing a picture of her daughters, Sandra talked about wanting sometimes to just *forget about cancer* but her strong sense of responsibility to be a voice for other Aboriginal women:

There are moments of panic when I just wanna look the other way, turn around and just run. So, um, I can't do that. It's just a thought though. It's nice, it's an escape, like watching TV...but, my heart won't let me [forget about cancer] because I have daughters. I've gone that way just to make sure that I do as much as I can to help my children and my grandchildren. And when I say mine, I don't just mean mine, I mean...I'm thinking of us all, like brothers and sisters.



Being part of change meant different things to different women. For some, this meant that they wanted to make themselves available to other Aboriginal women as a direct means of support, both as someone to talk to and to be there to help raise awareness:

I know how it feels...to have nobody to talk to...and I'd like to really help...or whatever it takes ...to help others.

The women wanted to see an increase in support services for Aboriginal women, including a way to connect to each other and support groups specifically run by and for Aboriginal women. This was a key reason why many of the women were participating in this study, and their appreciation of their new connections to each other was addressed again in the workshop and sharing circles. Tina said:

I need to tell you three [research team] in particular that you do not know how much that you have helped me. I didn't know these ladies before. I only knew Tina and other non-native people; and so I felt very alone and I will be forever thankful. Marion and I are only months apart...we talk about the stories and similarities...the aftercare problems that we are having...I hear Sandra's story and I hear myself over there...I hear the other ladies...all the other ladies that we haven't touched yet are longing for us as well.

Marion talked about wanting to start a support group in her community. Other women wanted to be part of the creation of support groups:

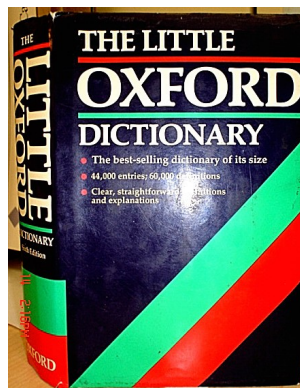
I would love to see a support group like...the cancer society with native people, to help native people.

For others this also meant raising money for women in their communities. And for others, this meant becoming an advocate through teaching and speaking out for all Aboriginal women survivors of breast cancer. Although Sandra, for example, talked about wanting to recoil and hide (discussed above), she also feels an obligation to represent Aboriginal peoples because, as she says, she has learned from her family to ask questions. This ability, she reiterates, is a privilege she does not take lightly:

...I need to, I need to speak for my mom because, she was so young when she left, you know, she just turned thirty in December and she died the following month. So, it's like you're so young and you had your whole life and all you wanted to do was see your grandchildren and I did.

The women hoped this project may become a means of informational support/awareness. Information was valued by all of the women as a means to understand more about the disease and helping women adjust. However, many of the women expressed strongly that the information was overwhelming, at times irrelevant and that they needed to have someone or something to help them sort through everything. Sandra creatively demonstrates the need for more and better relevant information with pictures of a dictionary:

I took a picture of dictionary, just because they talk in these damn words, when you're diagnosed that you have no clue. Like what the hell are you talking about? Like why don't you give me a book to, like, so I can decipher this.



Creating more information relevant to Aboriginal women was therefore seen as important and there was a hope that participating in this visual study may be part of this. All of the women said they participated in this study with the hope of doing something toward change for Aboriginal women with breast cancer.

Awareness was needed on a number of levels. First, to let other Aboriginal women know others existed and survived! The participants wanted their pictures to offer *images of hope* to other Aboriginal women, especially in more remote communities. Second, they talked about raising awareness so that more isolated women may check their breasts for

lumps or go for early screening. Third, part of their concern was also to eliminate the myths talked about here and in the earlier chapters that continue to surround cancer for First Nations peoples living on reserve. Some of the women talked about having others foremost in their minds when they took their pictures:

...Yeah, like I really struggled with the pictures and trying to think you know, what do I, oh my God, ladies, like I keep thinking about the ladies that were gonna look at these and, how can I help you? And what do you need to see? Like what do you, what do you want? Like um, and it's very difficult to try and think like another person.

A number of the women also wanted their pictures to take back to their communities to help raise awareness (and money) to support women there. One of the participants, Dorothy, spoke of using her own photovoice pictures as a fundraising initiative, to provide educational awareness about the problem of cancer in her community:

I want to make magnets [with two of my pictures]... I am going to put these in a clock, and put Island Lake Band welcomes you and use the money for the project...I want to make that money to be with the ladies that are surviving from cancer...I counted eight women there with different kinds of cancer—two with breast cancer... and there are those that don't want anyone to know about their illness. [I want them] to feel that they are not alone ...Alone there at home we get, we don't get travel dollars, money to pay our bills...the everyday money is not there.



6.3 Synthesis

The prominent social forces including race, space, gender, culture and socio-economics are shown to affect the Aboriginal women's experience of social support. The women's experiences and needs related to support are understood by them, in connection with the socio-cultural history of colonialism as well as other forms of power and privilege (including age¹³, gender and class).

There are important limitations to institutionalized support which have an impact on a very large percentage of women whose voices need consideration. These women declined services that they perceived to be racist (or threatening to how they saw themselves). Because the services worked on the assumption that all women's experiences

¹³ Many of the participants in this study were diagnosed at a relatively young age. This finding is discussed in detail in Thomas-MacLean, Poudrier and Brooks (2007).

of breast cancer were similar, the women perceived that there was a *catering to privileged white women* and many felt *unwelcome*. Many participants made an attempt to seek support from their local cancer support agencies or breast cancer support groups but did not return after that initial attempt. They also expressed their discomfort in being the only Aboriginal woman in the support group.

Because this is such a powerful theme, I recommend that additional research be conducted on 1) the potential for support groups specifically run by and for Aboriginal women; and 2) Aboriginal women's care-giving roles, especially those women in isolated communities and their potential to care for themselves. This investigation may be made possible in Saskatchewan because of support groups implemented as a result of this VBC research.

The potential for "culturally-relevant" support groups was studied in a similar research project with African American women in Rural North Carolina. Similar to the women in our study, the African American women expressed how uncomfortable they were with support groups offered by local cancer agencies and being the only African American women. These women expressed their shared desire to become involved in African American support groups, to share and address the concerns that they felt were different from the white women in the other groups and became involved in such groups (Wilmoth and Sanders, 2001). Those women who did participate in local self-help groups found that these sessions were a unique opportunity to share their own experiences with others who had similar concerns. Lopez et al. (2005a) argue that this opportunity was successful for the women and part of that success was the tendency of these women not to dwell on their own health problems, to ensure that they did not burden others. Similar to

the women in our study, these women focussed more on the needs of others than their own. Ahing-Giwa and Ganz (1997) similarly found in another breast cancer study with African American survivors, that their needs took a secondary role to others needs and caring for themselves was minimized. This led to ignoring and tolerating their own cancer symptoms and concerns.

Participants were concerned for women who did not face up to the disease. They wanted to find a way to reach isolated and silenced women who may not receive screening or early detection and may not complete their treatments. Future research with women on-reserves and in isolated communities was supported by participants and community members as an important next step in understanding the intricacies of ideological, historical and cultural underpinnings of cancer avoidance and increased fear. Literature on cancer and avoidance (see, for example, Stanton et al, 2002) suggests that cognitive avoidance actually increases stress and does not work very well as a coping strategy for breast cancer. Understanding avoidance and its impact may be understood in the context of cultural safety, which I examine in detail in chapter seven.

Although participants expressed personal identity issues and fears, the participants were not trapped in assumptions of inferiority, but demonstrated a strong critical analysis of societal inequality. This level of analysis was demonstrated by Sandra when she tried to educate the well-meaning middle class breast cancer survivors in her support group. Touched by the generous offer to buy her a bra, she said, *you just don't get it...are you going to buy us all bras?* Analysis of individual experience was linked to the experience and lives with other Aboriginal women. The women talked about financial inequalities especially those witnessed between themselves and other women in cancer support groups.

As we saw in Chapter 5, there were discussions about distress about not being able to afford to buy proper nutritious food, while sitting in a support group of women who are talking about healing on a trip with their family in Hawaii. There was also a contextualized understanding of social problems, evidenced by the ways colonial histories were linked to personal and relational issues.

With regards to physical changes, the women redefine their needs, recognizing gendered influence. The women talked explicitly about women's personal responsibility upholding gendered norms. Through these types of discussions they provided an ideological challenge to understanding the embodied experience. Although many of the women experienced deep loss with regards to their hair and their breasts, their analysis also challenges the idea that the post-mastectomy body must resemble their former physical exterior. Sandra, for example, talked about what a shame it was that losing both breasts and ovaries meant that she was losing everything that *made [her] a woman* and she talked about finding her own definition of womanhood; *[one must] find something inside yourself to be a woman*. The loss of her breasts seemed to open up an opportunity to appreciate 'womanhood' outside of the socially constructed gendered societal images. She said: *It's changed my life for the better. All of my relationships are so much sweeter. You can still feel like a beautiful woman without your breasts*. Rather than focussing on improving self through implants and prostheses, she challenged ideological norms and the ways that embodiment is constructed and upheld by even their own decisions to support them. This level of analysis, I argue, challenges cancer support networks which often focus on helping women to get back to their former image through reconstruction and prosthesis.

The importance of this type of gendered analysis was also presented by those women who did not mourn the loss of their breast. To those women, the focus on hair loss and breast loss was meaningless, and this mainstream focus from others (health care workers and society in general) was looked upon critically. Rather than assuming that women should conform to gendered identity by mourning breast loss and looking at the importance of implants or feeling “normal” these women challenged conformity and norms.

These participants’ words and pictures align with Lorde (1980), who writes about celebrating one breasted women. Her critique is that women are not supported to come to terms with the loss of a breast and the real impacts of the disease. Instead, women are taught to become part of a masquerade designed to supposedly make them feel better. She writes: “I am personally affronted by the message that I am only acceptable if I look right or “normal”, where those norms have nothing to do with my own perception of who I am...”. In this case “normal”, often means not only having the right shape, size and number of breasts and amount or length of hair, but also means the “right color” (Lorde, cancer 1980: 118). The message that one can be just as “good” as before is challenged, for a new message which celebrates difference and real beauty. Audre Lorde (1980) also argues that women should wear breast loss as a political sign, symbolic that not enough has been done by the powers that be towards breast cancer prevention. For Lorde (1980), this includes environmental and societal shifts.

Support related to physical changes then involves all levels of embodiment analysis, not simply helping women to return to their former bodies. This includes pain, loss, celebration, visible difference, real choices, culture, gender, socially constructed

normalcy, identity, acceptance of loss. This also draws attention to the importance of challenging socially constructed post-mastectomy and breast cancer norms, while making sure that the woman who chooses prosthesis, or silence through normalcy/invisibility, are not judged. Perhaps the opposite of such judgement is drawing attention to why the desire for breast implants and prosthesis are so strong, which would include an assessment of profit from such procedures, addressed through the political economy theory outlined in Chapter 2. This level of analysis challenges the socially constructed norms related to breast cancer and embodiment and the oppressive institutional forces which control women's bodies—nurses and breast cancer support workers silence women's bodies by suggesting that women wear prostheses and wigs. As Lorde (1997: 119) argues, this is “yet another episode in a long history of white, heteronormative institutions controlling [racialized and lesbian] women's bodies”.

My findings highlight the need for research in all areas (psycho-oncology, epidemiology, psycho-educational, medicine, feminism, sociology) and for policies/health care practices to respond to the women's complex identities, based on their histories of colonization, neo-colonialism and their need for support in the context of race, gender and class. This research has pragmatic implications towards developing informational resources which include Aboriginal women's voices and visual images and relevant support services.

In these last two chapters, I have shown how the women uncovered layers of analysis from; individual experiences: of fear, fear of recurrence, isolation, shame, resilience, hope and support; to an institutional analysis, discussing concerns with inequalities in race, class, and gender; to a historical contextual analysis which included the

burdens of colonial histories. In fact, I argue that the women in this research focussed more on social context than personal experience—potentially a characteristic of photovoice methodology where participants are encouraged to express critical consciousness. The women opened up analysis of the “multiple contexts” of their lives.

The women’s stories are not only about who they are but about how they are treated and the social forces which influence their lives. The following chapter focuses specifically on how the women have been treated, linking this to social forces within their lives.

Chapter 7 Visions of Cultural Safety: Revealing “taken for granted practices” that marginalize Aboriginal women’s voice

“It is how this group is perceived and treated that is relevant rather than the different things its members think or do.”¹⁴

This chapter is about social justice, race(ism), and breast cancer. As I have developed throughout the dissertation, *the Visualizing Breast Cancer* (VBC) participants have shown, through their visual images and stories, a powerful link between survivorship experiences and the intersection of history, race, gender, class and other social forces. It has become clear that the women’s stories are not only about who they are, and their individual, social and cultural beliefs, experiences, and needs. The women’s stories and pictures are also about how they have been treated, how this is linked to unequal power relationships and how their lives are connected to the legacy of colonialism and neo-colonialism. This chapter is an overview of how the women have been treated and how this is connected to their identity, well-being, and health.

Similar to Chapters 5 and 6, my findings highlight the intersection of prominent social forces, including colonial histories on the women’s lives. The difference in this chapter is that I focus specifically on the women’s perceptions of how they have been treated and how their identities are visualized and understood within health care services and beyond. Also similar to Chapters 5 and 6, this chapter demonstrates the strengths of anti-oppressive theory to understand Aboriginal women’s experiences. This chapter specifically demonstrates the value of postcolonial feminism and cultural safety as an

¹⁴Polascheck, 1998: 452; cited in Anderson et al., 2003: 199.

interpretive lens. Using the framework of postcolonial feminism and cultural safety, my interpretation of the data provides an understanding of how women have been identified, falsely identified, and how their identities have been decontextualized. I also show more specifically how Aboriginal women's health and breast cancer experience is a social justice issue. This framework adds to the analysis of support in Chapter 6 and psychological and physical role adjustments in Chapter 5. I show how consideration of identity and social justice underlies support networks and impacts survivorship adjustment.

Throughout this dissertation I have argued that the best analytical mileage is found by combining insight from different theoretical lenses. I have made links between the women's experiences and themes from social epidemiological, feminist, critical sociological and anti-oppressive literature on the effects of socio-economics, gender and race(ism) on physical/psychological survivorship experiences, support and support needs. In this chapter, I draw specifically on the anti-oppressive theory of postcolonial feminism. As I developed in Chapter 3, postcolonial feminism combines feminist, anti-racist and postcolonial discourse and questions the link between colonialism, neo-colonialism and the impact of race (ism) on the women's lives. Postcolonial and anti-racist discourse are theoretical perspectives which contest the historical construction of a racialized Other through colonization. Postcolonial feminism combines these anti-racist and postcolonial lenses with black feminism, which shows the intersecting forces of colonial histories, race, class, gender and other social forces on the women's lives. Black feminist scholarship also incorporates insights from other second and third wave feminist perspectives, especially standpoint and postmodern feminism (as outlined in Chapter 3). These feminist lenses draw attention to situated agencies and the importance of diversity. Postcolonial-feminist

scholarship then bridges postcolonial, anti-racist and black feminist scholarship, developing “how colonial and neo-colonial policies/practices are being played out in contemporary social life” (Anderson et al., 2003: 200).

In order to link these abstract theoretical lenses to the everyday experience of the research participants, I apply the postcolonial concept of cultural safety. As I briefly outlined in Chapter 3, cultural safety was introduced by Indigenous nurses in the postcolonial context of New Zealand. Cultural safety was reworked by postcolonial-feminist and other critical authors in Canada (see, for example, Anderson et al., 2003; Browne, Fiske and Thomas, 2000) as a lens to explore inequalities and institutional and individual discrimination resulting from colonization.

7.1 Cultural Safety

Cultural safety is used as a lens to assess interactions between health care professionals and Indigenous peoples. Cultural safety is also a tool which allows health care professionals to question how their beliefs and their treatment of Indigenous peoples are embedded in colonial power relationships. In general, this idea of cultural safety is that researchers, policy makers and health care workers, ensure the effect of history, especially colonization, is understood when addressing health concerns (Browne and Fiske, 2001).

In the Canadian context, a number of authors have used cultural safety to explore relationships between First Nations people and health care workers. This research has analyzed culturally safe and culturally unsafe practices from the perspectives of First Nations peoples and health care workers. 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. For example, Anderson et al. (2003: 196) uses the concept of cultural safety to “think critically” about themselves as health care workers to be “mindful of [their] own sociocultural, economic, and historical location” and how this affects their work with marginalized and racialized patients.

This chapter extends the use of cultural safety to analyze the women’s stories and pictures in the VBC research. Because cultural safety simultaneously views individuals in their locations, related to colonial marginalization, I argue that it offers a unique lens to understand the women’s stories and pictures. I identify culturally unsafe and culturally safe practices arising from the women’s stories and pictures, inside and outside of healthcare, based in the framework of post-colonial feminism.

This lens does not offer an understanding of differences, essentialized, static or cultural categories, belief systems from people of different ethno-cultural backgrounds. Rather than questioning what people think or do, or provide a cataloguing of culture-specific beliefs, the focus of cultural safety is on how people are treated and perceived and how this is linked to inequitable social relationships. I employ principles of cultural safety and postcolonial feminism to understand structural barriers the women encountered and their health and social implications.

The following section begins to address how to move from the conceptual/theoretically informed concept of cultural safety to the everyday experiences, visual images and stories of the women. Findings point to the complexity of reading cultural safety. I begin by outlining specific definitions of cultural safety, from the literature.

7.2 Conceptualizing Cultural Safety

Authors of cultural safety define it by talking about culturally unsafe and safe practice. Culturally unsafe practice is defined as: any actions which diminish, demean, or disempower the cultural identity and well being of an individual (Whanau Kawa Whakaruruhau, 1991; cited in Anderson, 2003)—the three D’s (Wood and Schwass, 1993). Culturally safe practices “recognize, respect and acknowledge the rights of others” (Cooney, 1994: 6; cited in Brown, Fiske and Thomas, 2000: 9)—the three R’s (Wood and Schwass, 1993). Applying the lens of postcolonial feminism to cultural safety draws attention to social positioning within historical and social changes. Postcolonial feminism points to cultural identities being subordinated through processes of culturalization, Othering and routine racialization practices.

The postcolonial-feminist perspective and cultural safety helps unravel the complex ways the women have had their rights respected or have been disempowered and how this treatment has affected their health and well-being. Cultural safety therefore may reveal “taken for granted processes and practices that continue to marginalize Aboriginal voices and needs” (Anderson et al., 2003: 199). Unlike identifying and naming the other conceptual categories within this research, such as fear, fear of recurrence, support, resilience, this concept is not as initially transparent, but involved interpretive work.

7.3 Applying Cultural Safety

Based on the findings and using categories elicited from the cultural safety literature, four broad themes regarding culturally unsafe practices emerged. These are: 1. not being visible and hiding identities (dismissed); 2. being wrongly identified; 3. racialization and discrimination; and 4. lives without context (demeaned and disempowered). Using the framework of cultural safety, two themes evolved. These are: 1. the importance of being visible (recognition); and 2. being correctly identified/applying cultural safety (respect and rights). My conclusion includes an assessment of photovoice research using the same lens of cultural safety.

7.3.1 Cultural Unsafe Practice:

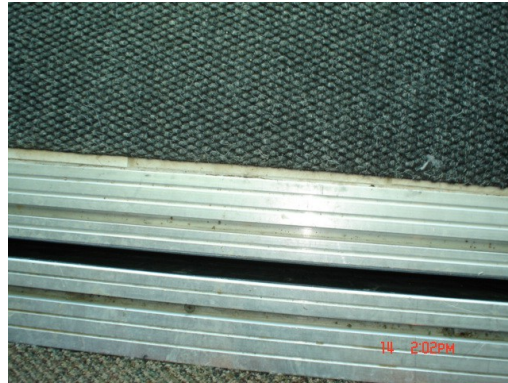
7.3.1.1 Not Being Visible and Hiding Identities

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:



...which is what I felt like our, that's what's happening to us. 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 elevator everyday. But very few people will look in the cracks to see what's down there, or look in there.

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

Themes related to cultural safety and not being seen were also addressed by participants who talked about cancer fundraisers and breast cancer activism. Dorothy, for example, said that although her own community has helped raise money through cancer runs and other fundraisers, they never receive any of it. And, she said, their need for funds is not acknowledged or seen. Dorothy's critique questions why more mainstream fundraisers are not directed at community health measures:

They raised [the money] in the community but [the community] didn't get no contributions. Someone from the community could use those funds. Why are we doing this...why can we not help our community members to use that money—financially help out the people...[One of the teachers aides said] “We should give that money to Dorothy”...These runs make billions of dollars through the years...but we don't get [anything]. ...we don't get travel dollars, money to pay our bills...the everyday money is not there.

Similarly, as discussed in Chapter 6, 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 workers, nurses and social workers. The participants felt their beliefs and practices were dismissed, not responded to well and felt they risked being told not to practice them. 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.

Participants who healed themselves through alternative practices, such as Mary, Margaret, Marie and Dorothy (discussed in Chapter 6) and who did not follow specific medical orders, felt that they were at risk for being labelled irresponsible. They had to hide this part of their identity, rather than embrace it.

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. The reality of their lives and lifestyles were understood outside of the context of social forces, as shown below.

7.3.1.2 Wrongly Identified

The women introduced a dichotomy of wanting to be seen and not being too visible. There were worries about being falsely identified and misunderstood. Their concerns were about: false generalizations/stereotypes of lifestyles and cultures; misunderstanding of diversity, spirituality and traditional medicine; and de-contextualized identities. Thus, being seen was also part of racism and Othering.

The picture of Sandra in the bare skin tipi is symbolic of identity, showing an intermingling of the past and the present, and her fear of being wrongly identified. Sandra described a number of things about this picture. First, the university in the background is where she received her degree. Second, the skins missing on the tipi, which Sandra tells us

is symbolic of being exposed to false and harmful generalizations. She is trying to hide and explains, *you can very much see that I am an Indian:*



This one... is a tipi. It's a skeleton, the skins are missing, so I'm exposed is what I'm saying...you see the past...and the present. That's me inside of there though, you know? 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, you know? This is where I went to university too. That's where I got my degree.

Sandra's picture of herself in a tipi was shown in Chapter five when addressing a theme related to fear of cancer recurrence. She talked about the snow sleeping, like her cancer slept. Common with photovoice is that there are often many meanings embedded within one picture. This makes it necessary to occasionally show the same picture twice.

False generalizations/assumptions about culture, spirituality and being an "Indian" were defined as racist. The women have diverse spirituality, different teachings and experience with traditional culture. Sandra reinforces this theme when she talks about

not being “*beads and feathers Indians...we’re just people*”. Her picture of “*Indian art*” was taken to symbolize that although people think “...*that we are just beads and feathers...we’re not...*”:



... I’m a person just like anybody else...I don’t speak to animals and I don’t know the answers to everything... I’m like, “No, I’m not a beads and feathers person”.

I would assume that this is not what someone would say about this photo if this was shown to them in the context of this project without Sandra’s words to explain what she meant. This is especially important to consider in relation to the dissemination of the photovoice display.

The women also talked about being wrongly identified through generalizations related to culture. The women acknowledged that many Aboriginal people have very strong First Nations spirituality. They also said that there are many cultural differences, traditional teachings and practices and that these have been reshaped through colonial histories:

This is our spirituality and...some people will just perform for you, for white people...cause that’s what you do... you put your regalia on. You know ...there was a time it was for spiritual dances and for things like that, now it’s more of an entertainment thing... for others.

Relayed in the women's image and words are the need to recognize diversity and the ways that identities have shifted with colonization. This includes performing for others, and hiding from stereotypes.

My next example shows participants description of feeling falsely identified and Othered in cancer support groups. Although I discussed problems with cancer support groups in Chapter 6, 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 feelings that they had no support. Four of the women talked about feeling invisible or out of place within existing support groups. These women 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, I just wanted to take and say, you know what, there's the carnation in the middle of all those roses which is kind of what I felt like sometimes. You know, like... when I'm sitting in a group of all of these Caucasian women... I just felt like, you know their all so perfect and everything, and, and they're so beautiful and they're so lucky to be, to be privileged.



She 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 implies here that the rose and carnations 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, going on holidays like 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. This leads into the next major themes; racialization, discrimination and lives without context.

7.3.1.3 Racialization and Discrimination

Culturally unsafe practice was also expressed through shared experiences of racialization and racial discrimination. The concept of racialization is used to recognize processes whereby groups of people and their practices are identified through physical characteristics (Reimer Kirkham, 2000). Cheryl and Marjorie talk about experiences with government agencies, including health care settings.

Cheryl connected her financial stresses to her experience as an Aboriginal women and being defined through stereotypical and racial terms. She experienced discriminatory treatment when dealing with government programs. 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 and 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:

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?" ... And I said this is short term. I said I am able to go back to work once my doctor says I can.

Cheryl was the only VBC participant who did not feel that being an Aboriginal woman made her cancer experience different from non-Aboriginal women. Paradoxically, although the aim of the VBC research was to understand the perspective of Aboriginal women, there was a very fine balance between ensuring that the women's voices are heard, and being guilty of culturalism.

Marjorie's example of discrimination with a health care professional reveals the complexity of what it means to be sensitive to 'race' in health care communications (Poudrier and Thomas-MacLean, in press). Marjorie recalls one of the nursing staff referring to *her kind*. She shares her memory of what this nurse said to her:

The nurses could be very patronizing...Not taking anything away from them. They were good at their jobs. They were good nurses... When [one training nurse] got to me, [she's] like: "Gee that's kind of hard on you huh? We don't really see your kind here none too much".

It seems being a "good nurse" does not require a cultural safety framework. Marjorie 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? Give me the concept or the thought behind what you've said." ...She was a training nurse. She got me ...I, I was so fucking pissed off..

All of the women agreed on the importance of health care and other professionals being sensitive to experiences of racism. Cheryl and Marjorie's reflections above relate to their experience of racism and being Othered by identifying race without sensitivity to heterogeneity. This also draws attention to the importance of identifying social context.

7.3.1.4 Lives Without Context

The VBC participants articulated a lack of visual representation, a lack of recognition for personal, cultural and social circumstances, and being falsely identified all of which contributed to a feeling of being dismissed. 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. As outlined in Chapter 5 and 6, 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. 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 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 and other participants said that these are false and harmful generalizations. They explained that many Aboriginal women and Aboriginal people are not simply silent but have been silenced.

7.3.1.5 Decontextualized Silence

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*. 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 spoke about women being unwilling to do self-examinations or to even talk about cancer. Marjorie, for example, says:

With us there has been so much intergenerational damage...everything is very hush hush...we need to tell [each other] it is ok to take your shirt off and bra off—so what if you are lop sided, you are alive...but we have been hushed...that's how I view myself—the package is a little scuffed up...but I am here...I am alive.

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. I had to do it myself. That was the hardest thing for me, was staying strong.

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 don't put my hand up in school because I didn't want them to think I was stupid.

She makes the link between her history and not asking questions and the 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 or 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 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:

...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.

Sandra and Marion's identities as being both silenced, but also finding their voices, identifies another important theme—that people 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 leads to themes on cultural safe practices, which provide a direct contrast to culturally unsafe practices.

7.3.2 Culturally Safe Practices

Themes related to culturally safe practices are: 1. the importance of being visible (recognition); and 2. being correctly identified/applying context and cultural safety (respect and rights).

7.3.2.1 The Importance of Being Visible

Aboriginal women's visual images and voices have been marginalized and their concerns have not been addressed. As developed above, many of the VBC women have identified this neglect as part of racism. The women's shared desires are to be visible (recognized) and identified correctly (respected and rights)—symbolic of the three R's of cultural safety.

All of the women talked about the importance of recognizing diversity and difference amongst Aboriginal people, while recognizing similarities in experience and treatment. Sandra states:

It is hard to lose pieces of yourself, and we have to look at...different cultural [practices]...but there are so many First Nations people, different languages, different cultures. Although there are a lot of similarities, there's some great differences too.

The women spoke of having respect for diversity amongst themselves and Aboriginal peoples in general. Respect was presented in a number of ways. Sandra, for example, discussed her own respect for the intelligence of those who are taught in more traditional ways of knowing and those Aboriginal peoples who have become educated in Western education:

We're very diverse type of people in Saskatchewan... I mean you have people that are very well educated in the Western education and those that are not but that doesn't mean that they're any less intelligent... they could be more... schooled in, in our traditional ways of thinking and learning and medicines and all of that kind of stuff.

The women shared concerns that the diverse ways of knowing were not equally respected in the larger society. False generalizations and assumptions about culture and being an “Indian” are defined in postcolonialist discourse as a process of racialization (Johnson et al, 2004). The women articulated how they were denied their full identities through racialization.

Importantly, this photovoice research was seen by the women as having pragmatic implications towards developing informational resources which include Aboriginal women’s voices and visual images. As discussed throughout, the VBC participants discussed how important it was to bring forth their voices and images and to reach other Aboriginal women, especially isolated women. The women called for more inclusive materials, recognizing: spiritual customs, alternative medicine, cultural beliefs, cultural and regional heterogeneity, language barriers, cultural myths and an inclusion of anecdotal survivor stories of Aboriginal peoples. Most importantly all of the women wanted to let other Aboriginal women survivors know they are not alone.

The women were also hopeful that the photovoice process would help develop more culturally safe forms of support. The women wanted to see an increase in support services for Aboriginal women, including a way to connect to each other and support groups specifically run by and for Aboriginal women. This was a key reason why many of the women were participating in this study, and their appreciation of their new connections to each other was addressed again in the workshop and sharing circles.

7.3.2.2 Being Correctly Identified/ Applying Cultural Safety

Most of the VBC women identified the importance of Aboriginal women's lives being understood within the context of history and social inequalities. All of the women identified the importance of understanding differences and diverse means of coping. For example, all (but one) of the participants talked about violence against Aboriginal women and their cultures, through experiences, such as residential schools and residential day schools, and through continued realities of racism. The majority of these women also linked these histories to their experiences of intimate partner and family violence and to the responsibilities/burdens that Aboriginal women face in relation to their families emotional and financial care. Their stories also reflect very diverse ways of coping and responding to this violence against them.

Although all of the women spoke about being a survivor of intimate partner violence, childhood abuse and/or residential school violence, some of the women said this contributed to their silence, but many of the women also said that this contributed to resilience and strength to overcome and fight cancer. All of their words are powerful and humbling. Cheryl, for example, said:

I've been 25 years with an abusive husband verbally. So I guess that I had to be strong. If I could live through that, I thought that chemo would be easy.

Sandra similarly shares:

Cancer rocked my soul like my husband did—beat me and cancer did the same, it beat me.

Histories of residential schools were also linked to personal resilience:

I am a residential school survivor and come from four generations of residential school survivors. I got a lot of beatings. I would fight back. I fought back against cancer too. (Marjorie)

Marjorie explains:

In boarding school, they could say oh you're this, you're that, you stupid, whatever. And it's like granted it may be so in your opinion and it, I may not be able to grasp how to do this, this, or this, but hey, there is something else in me that have opened up and brought forward...have me looking back when I'm fifty years old saying, hey I'm still here. You know, like what you tried to beat down in me, you brought something up that's been hidden right along and I'm a better person for it.

A lack of recognition of personal and social circumstances contributed to a feeling of being invalidated and not seen. There was a concern that social problems may be linked to individuals or cultures, rather than understood within historical and social context. On the flip side then, the women realized the importance of being identified in the context of history and social forces that affect their lives. The women are therefore defining themes related to culturally safe treatment as: being identified; being correctly identified, respected; and having identities understood within historical and social context, directly incorporating the lens of cultural safety.

7.4 Synthesis

In sum, the women's stories and pictures define culturally unsafe practices as: ways in which they were not seen (denied); misunderstood (demeaned); and lives decontextualized (disempowered). In this same way themes related to cultural safety were: being visible (recognized); lives contextualized (respect and rights).

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 health.

Analyzing what leaves people feeling safe or unsafe allowed analysis of treatment, personal analysis of the affects of racialization, Othering and the different contexts of suffering and power. I am also reminded that hard categories of colonized and colonizer must be revisited. Following postcolonial feminism, social categories and access to resources are fluid and dynamic. Aboriginal women and Aboriginal men, similarly to Caucasian women and men may lie within categories considered the oppressed or oppressor (Anderson et al., 2003). The participants have diverse experiences of social, economic, political oppression as well as diverse experiences of social, economic and political power. The women have been silenced and/or have enhanced their voice and found strength, through their experiences of residential schools, residential day schools, violence against their culture, violence against themselves and experiences of discrimination and racism. This emphasizes the importance of intersecting and complex social and economic relations, and social agency. This does not minimize the impact of colonial histories and oppression –nor “the importance of critical race and gender analysis” (Anderson et al., 2003: 201), but points to the importance for the concepts we employ to handle complex social forces and multiple agencies.

This 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 to look beyond descriptive cultural difference or cultural sensitivity to gain deeper understanding of social forces and factors which influence Aboriginal women’s lives and lives of their community. 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-economics; central care-giving role held by many

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

Information about breast cancer is criticized as assuming that all women are the same (see, for example, Friedman et al., 2007). 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 (Harraway, 1999; cited in Poudrier and Thomas-MacLean, in press). Visual images may have transformative potential (Pink, 2001), “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, in press). The potential for this study to offer visual images and make visible the often marginalized voice of Aboriginal women breast cancer survivors, however, is yet to be fully realized.

Voices of Aboriginal women introduce a new knowledge about breast cancer survivorship from which policy change could result, and this is addressed in the following chapter. I speculate that these images will not be seen in a way which is culturally safe, unless the lens of cultural safety is used to view them. In Chapter 8, I offer a warning about the political or social change potential of photovoice research of empowering and visual methods like photovoice. I address policy suggestions and the potential of empowerment models of research.

Chapter 8 Moving Forward Cautiously: A Critical Assessment of the Promise of Photovoice and Social Change

*Each time I share my story I feel stronger...
and each time we hear another's story I feel stronger...
Martin Luther King [said]...the voices of thousands are hard to ignore.
We need to hear each other...[even if] it is a loud silence, that is great.(Sandra)*

Finding solutions together is a theme of photovoice. As discussed in Chapter 4, the VBC women's response to the photovoice project was very positive: *This was a wonderful, wonderful exercise... ; ...it was a powerful exercise, I really liked it.* (Shelley) The women saw the potential of photovoice research to assist them to work together towards helping other Aboriginal women breast cancer survivors: *I pictured right away that it would help others.* (Dorothy) A goal of photovoice, and a key component of research with Aboriginal peoples, is that participants benefit from their involvement individually, socially and politically. Participants are empowered to represent and enhance their communities through the documentation of their life experience through photography (Wang and Burris, 1997):

With this technique, people capture images of their everyday life experiences in their communities through the use of a camera. By telling the story behind a photograph, they describe life in their communities and thus convey to others the context of their lives from the personal points of view. (Moffit and Robinson, 2004: 2)

This last chapter has two parts. In the first section, I outline key recommendations for future research and social change/policy which evolved in the research. This section also includes a discussion about what has happened since the completion of the photovoice research, the final community focus group and sharing circle. In the second section, I situate the research findings and photovoice method in the context of historical, social, political and economic inequalities, by drawing on the insights of anti-oppressive and governmentality theory. Specifying questions and insights from these theories allows the

recommendations from the women, along with the themes addressed throughout the dissertation, to be contextualized within current structures of power and domination. This provides a caution towards proceeding with photovoice research findings and a critical understanding of participants as “empowered citizens”.

Specifically anti-oppressive theories such as postcolonial feminism, cautions that the notion of “empowered citizens” must be understood in the context of neo-liberal inequalities and unequal power relations (Fiske and Browne, 2006). The problem is that the dialogue with the new “empowered citizens” is between unequal parties. Drawing on anti-oppressive concepts such as culturalism and cultural safety, I caution that those that hold the cultural, economic and human resources determine how the dialogue proceeds. It is here that I re-introduce the analysis from the critical governmentality perspective, which provide warnings about the changing nature of citizenry and political dissent—elaborating how public dissent which challenges the status quo is defined as “unbecoming of the new responsabilized citizen”. Offering a voice to people on the margins without shifting relations of power, adds support to the status quo, rather than challenging it. What I describe is a complicated process of social control—demonstrated through a combination of critical frameworks, including the women’s. First, however, I provide a review of recommendations and research findings.

8.1 Recommendations from the Women at the Community Focus Group and Sharing Circle

The workshop and sharing circle at the end of the research project, was the initial step towards the *Visualizing Breast Cancer* (VBC) participants working together and developing solutions—since this was the first time they had the opportunity to meet. The women’s sharing circle was the last step of the funded research by the research team, but the first step of the coming together of women who now have an opportunity to move forward with support work. It is for these reasons also that the second part of the day of the sharing circle was for a community focus group where invested community members were invited, as outlined in Chapter 4.

Three outcomes of the initial community event are evident. First, relationships were established between Aboriginal breast cancer survivors in Saskatchewan and between the interested community members, with hopes to extend this list. Second, findings were shared with interested stakeholders and the community groups which built capacity in the area of Aboriginal women’s experiences with breast cancer. And third, the findings were disseminated to the community members helping to raise awareness of Aboriginal breast cancer survivor experiences.

A number of very ambitious themes/directives were established in the workshop and sharing circle (and talked about in many of the second in-depth qualitative interviews). The first themes were fundraising, support and policy work—finding ways to keep this group together and to provide more support (through support groups and other health care initiatives) to other newly diagnosed Aboriginal women and breast cancer survivors. As developed in Chapter 5 and 6, the women wanted to see an increase in support services for

Aboriginal women, including a way to connect to each other and to initiate support groups specifically run by and for Aboriginal women. The women also discussed wanting more support within health care services, specifically to meet the needs of Aboriginal women. This included expanding the services of Native Liason workers. The role of a Native Liason 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 and to act as an advocate for the patients. Other participants also spoke about wanting to volunteer at the cancer agency, simply to be there for other Aboriginal people when they came to the cancer center.

The second sharing circle themes were about advocacy, educational awareness and photo exhibits. The photo exhibit of the participant's photographs was intended to be created in collaboration with the community advocates and participants and disseminated in a way appropriate for the participants. As discussed in Chapter 6 and 7, a number of the participants in VBC said they felt breast cancer was represented in the media as an older white woman's illness. The women discussed together how important it was to bring forth their voices and images and to reach other Aboriginal women, especially isolated women in remote areas in a way that may be meaningful. The women called for more inclusive materials, recognizing: spiritual customs, alternative medicine, cultural beliefs, cultural and regional heterogeneity, language barriers and an inclusion of anecdotal survivor stories of Aboriginal peoples.

For some of the participants, education of community and health care workers also meant awareness about how their experiences of racism and discrimination during treatment, income loss, poverty and moving into the city from the reserve affected their

ability to care for themselves during treatment. As discussed in Chapter 7, this was especially important because many Aboriginal women may not ask for support or speak out because they *have been silenced*.

The women felt their visual images would be a powerful tool to raise awareness amongst other Aboriginal women and amongst care-givers. The women suggested that their photovoice exhibit could be used by breast cancer advocates and the screening programs in Saskatchewan to reach remote communities and areas. The women spoke of wanting to use the travelling exhibit that had been initially planned by the research team [using the photovoice pictures] and many wanted to work on developing a video.

8.2 What has happened since?

Despite some awareness that the needs of Aboriginal breast cancer survivors may be unique and the women may be underserved, there have been few opportunities for Aboriginal survivors in Saskatchewan to come together as a collective. The community partners from the Saskatoon Health Region, Breast Health Centre, Breast Cancer Action Saskatchewan and Breast Cancer Community of Stakeholders, who participated in the sharing circle and workshop were very interested in learning about Aboriginal women's experiences, and have not had a great deal of opportunity in the past to do so.

This initial sharing circle resulted in a number of other initiatives. The education coordinator for the Breast Cancer Screening Program in Saskatchewan met the researcher and a few of the participants to discuss ways to more appropriately represent Aboriginal women in Saskatchewan. The co-ordinator will also discuss ways to work with Aboriginal women in more remote Saskatchewan communities, and is interested in using some of the visual images created by VBC participants (for media and educational materials).

Most recently, The Canadian Cancer Society has approved a grant, “The Living Network: Sustaining Our Collaboration; Broadening Our Reach”, submitted by the Breast Cancer Community of Stakeholders (by Peg Schmidt, who attended the community focus group), to bring the women together again, facilitate an Aboriginal Women’s Breast Cancer Advisory Committee for Saskatchewan. The Saskatchewan Breast Cancer Network is a Canadian Breast Cancer Initiative, affiliated with the Public Health Agency of Canada which is funded by the Canadian Cancer society. The network’s purpose is to increase awareness, information and support for those concerned with breast cancer and breast health. After extensive involvement with the research team and attending the sharing circle/workshop, the Network applied for and received funding towards improving the awareness/education and support needs for Aboriginal women in Saskatchewan. The objectives were to build on the momentum that had been established in the VBC project and develop: 1) an Aboriginal women’s workshop; 2) Aboriginal women’s working group (which were all participants from the VBC research); and 3) develop and work on a recommendation document and work towards dissemination.

Two events have been hosted to bring the participants together again, and towards the development of an advisory network. The initial gathering focussed on recommendations for Aboriginal women’s survivorship and well-being. This was also an opportunity for the women to come together again as a group. A few other Aboriginal women were also invited and attended, increasing the opportunity for connections amongst the women. The second event was an opportunity for the women to gather at the larger Living with Cancer conference held in Saskatoon in April, 2008. This annual conference is for cancer survivors and offers information and tools to assist their cancer journey and

survivorship. This was an opportunity for the women to come together and for the photovoice pictures to be seen for the first time (outside of the sharing circle).

Together with the co-ordinator of the Breast Cancer Community of Stakeholders and advisor for “The Living Network”, Peg Schmidt, four large posters were designed, with the words and the pictures of the Aboriginal women. The themes that were on the posters reiterate themes in this thesis—a) resilience and strength; b) support; c) surviving breast cancer; and d) the importance of families. Alongside the posters was one picture chosen from each of the women’s interviews as a picture that she would like shown and the quotation from her interview that went with that picture.

I designed the posters and chose the themes for display and chose the pictures and quotations for each woman, but these were chosen based on the women’s interviews and their self-selected pictures. The grant held by the Saskatchewan Breast cancer network paid for the printing, and will now use these towards future education about Aboriginal women’s survivorship around Saskatchewan. The women spoke of the event being a success and the five women I spoke to said they were proud of the display.

The photovoice display was also being shown at a June 26th, 2008 event: “Connecting the Breast Cancer Community” in Saskatoon at the Delta Bessborough hotel. The goal of this conference was to connect survivors, share stories, information, review projects of the Saskatchewan Breast Cancer Network and view the photovoice display featuring the VBC participants.

While I sincerely acknowledge the individual, relational and political benefits of this photovoice project, my critical theoretical lenses indicate that we must proceed with caution. I conclude this work by situating the research method, proposals towards change,

words and pictures of the women, and the photovoice displays, in historical, political and economic context. I combine anti-oppressive and governmentality theories towards an interrogation of relationships of power.

8.3 The Paradox of Empowering Aboriginal Women in a Political Context of Culturalism and Governmentality

Drawing on anti-oppressive theories, specifically postcolonial feminism, I argue that empowering the women towards involvement within health education and policy development, risks “discrediting them” (Fiske and Browne, 2007). The idea of culturalism is important here. Culturalism defines how social problems become defined as cultural difference. Under the guise of acknowledging cultural diversity and empowering marginalized citizens, a group identity becomes socially defined, new subjective identities are proscribed (McConaghy, 2000) and these identities are used to stereotype and discredit. This is precisely the same warning from the women in this previous chapter who wanted to be respected for their diversity, drawing attention to problems of Othering Aboriginal people and Aboriginal culture. This analysis is now applied to the entire study and the potential for photovoice and empowerment politics to be involved in social justice and change.

8.3.1 Postcolonial Feminism and Culturalism

Postcolonial-feminist theories understand everyday realities and lives as contextualized within social relations including race, gender, class and age (Anderson et al., 2003). The question becomes how colonial and neo-colonial histories continue to influence the contemporary neo-liberal context and how this influences everyday reality. Accordingly, the promise of “empowerment politics”, promised in photovoice research methods and the proposals towards change from the women in this VBC research must be understood within this political and socio-economic context.

Following postcolonial-feminist theories, I provide a critical understanding of “culture” (Anderson et al., 2003). As I introduced in Chapter 2, “culture” is not a politically neutral concept or simply a set of practices and beliefs. Culture is imbued with historical and political meaning, usually associated with social constructions related to race and racism. Dominant groups have re-defined meanings of local peoples and are responsible for shaping structures which define cultural differences, including health care. Part of the problem of culturalism is identifying how particular “social problems” become marked as Aboriginal or cultural problems, and herein lies the caveat towards “empowerment politics”. Previous research on Aboriginal self-government has shown how Aboriginal Governors are recognized as governing citizens with “specific ill health”, usually seen as “urgent moral needs”, rather than being viewed as governors of “citizens of good health”. Non-Aboriginal governors, on the other hand, are not similarly forced to contend with what Aboriginal governors may recognize as urgent needs in non-Aboriginal communities. In other words, “white” governors are “dissociated from discredited subjects” and not

contending with health issues directly associated with racialized identities. Aboriginal governors, on the other hand, “are associated with discredited racial subjects as defined by racial ethnic identity” (Fiske and Browne, 2006: 98). ‘Ministerial’ language and practices emerge in a way which Others and racializes entire groups of people (Fiske and Browne, 2006).

It is in this context that policy informed by empowered citizens must be understood. Culturalism warns that the decision about empowered visions and policy suggestions are embedded in power relations. Fiske and Browne (2006) show a paradox between Aboriginal women empowered to enter into a dialogue towards health policy reform and the ways this dialogue discredits them, acting against their legitimacy or right to hold power. This dialogue (which is between unequal citizens) empowers Aboriginal women to share their stories. The problem is that their stories are interpreted by those in power and this is often done in ways which discredits Aboriginal people, linking social problems to racialized subjects or as evidence of racialized cultures. Lifestyle and culture become the problem. This is evidenced in Canadian research which often glosses over heterogeneity and social context, linking Aboriginal culture with social problems related to poverty, dependency, addiction and poor health (Browne and Fiske, 2001; Tait, 2000; Browne, Smye and Varcoe, 2007). Previous research has also shown that specific needs related to socio-economics, employment, family, environment, and support have also been used to discredit Aboriginal women (Fiske and Browne, 2006).

Browne (2008) provides examples of the danger of mainstream health care workers misinterpretation (culturation) of social realities of Native peoples. She shares health care providers’ ideas from her previous research: “I find with Native people just the way their

culture is, I think you get a lot more social things that you need to deal with.”... “It is in their culture to have a lot of violence, stabbing, alcohol abuse...more than what you see in other cultures.” This process attributes health and social problems to culture, which is therefore a form of racism and Othering. Fiske and Browne’s (2006) research provides an additional warning about health care’s interpretation of Aboriginal women’s silence and their feelings of not belonging. They argue that the women’s silence may be misinterpreted by health care professionals as “shamefulness or a type of submission” and deemed as cultural difference: “Silence means a woman will not speak to her own pain, will not disclose her own health needs...silence is all too often read as shyness, while shamefulness and submission, which in themselves are moralizing tags, are used to identify cultural difference” (Fiske and Browne, 2006: 104). Similarly, outrage or inappropriate language or behaviour in the medical setting also becomes tagged as cultural difference.

In the VBC research there are two interpretations of the outrage, silence, poverty, homelessness, conditions on reserves and other social problems that the women talked about. On the one hand, the women’s anger and silence may be understood in the context of systemic oppression and a life history of violence within residential schools, racism within the community, disenfranchisement through the welfare system and healthcare. On the other hand, silence and anger could become wrongly interpreted as lack of “social mannerisms that define insider status...[and] undermine a patient’s credibility”. As Fiske and Browne (2006: 104) explain: “Women’s social agendas must...“match” the clinic’s agenda. To do otherwise is to be viewed as Other in terms of one’s class, culture and knowledge.” This latter process of culturalism furthers social distance, tension and increases Othering of Aboriginal women. All of this is dangerous to the women’s health

needs. The women are identified in a moralistic framework, discredited in the medical community, tagged as submissive or violent. My question becomes how to bring forth the women's images of social problems without having these read in this moralizing framework.

A further problem is that many Aboriginal people *are* located on the margins of the political economy and this is related to their unequal health status (Waldram, Herring and Young, 2006). This is also, however, related to their depiction as the Other within health systems (Browne and Fiske, 2001; Browne, Smye and Varcoe, 2007). This alerts us to the importance of acknowledging inequalities, while not creating further difference and Othering. Worst case scenarios have been misused as symbolic of pathological peoples and culture, and attention is taken from wider economic, social, historic and economic contexts of peoples lives. "Culturalism diverts our attention" (Browne, 2008: 10) from "the burden of history" (ibid: 9) and constructs people as "more different [from "us"] than they really are" (Varcoe and McCormick, 2007; cited in Browne, 2008: 11). I argue that the Photovoice images risk becoming stereotypes of Aboriginal peoples and culture, while the impact of colonialism and social violence against them remains hidden.

It is in this context therefore that we need to understand our VBC photovoice research and the participants' willingness to become part of policy development. The voices and pictures that the women worked hard to contribute are at risk of being interpreted through culturalist discourse. Policy initiatives from the VBC women and photovoice findings recommend governance in four specific areas related to: information, representation; relationship building; and Aboriginal health components. What is suggested are that health providers and governors initiate educational and training programs on health

issues and anti-racism, teachings of Aboriginal history and cross-cultural awareness. It is fundamental that this information is not presented as a means of curation, or defining people by the problems they face. This does not mean, however, that we omit discussions on continued problems that exist because of colonization and historical oppressions. However, sensitizing teachings and defining 'culture' as the problem, is not a remedy for colonialism. Health care realities of Aboriginal people must therefore also be linked to the effect of colonization and neo-colonialism, recognizing the burden of history: forced assimilation of Aboriginal peoples through appropriating lands, outlawing spiritual and cultural practices, forced indoctrination into dominant culture through residential schools, forced marginalization onto reserves and continued discrimination and racism. As I have developed previously, this approach is defined in the literature on health care with Aboriginal peoples as cultural safety (Browne, 2008; Browne, Smye and Varcoe, 2007; Fiske and Browne, 2001).

I argue the photovoice pictures in this study must be understood using this lens of cultural safety. This means that the stories and visual images of the women include an understanding of histories of colonization and neo-colonialism, marginalization and intersectionality of race, class and gender and the impact of their lives and health care. I therefore advocate moving ahead cautiously. This also means revisiting the purpose of sharing circles and community displays/focus groups within photovoice research.

I conclude the dissertation and this chapter with one final level of analysis, which places photovoice and empowerment politics/educational models within the political context of neo-liberalism and increasing inequalities. It is this context which shapes the photovoice research, its dissemination and potential for social change. I caution that breast

cancer research and activism may maintain the status quo, under the guise of empowering citizens to be involved in social action and change (King, 2003).

8.3.2 Governmentality

Questions deepen as we address whether or not change is possible, or if empowered community members can become radical activists and address the root of the problems suggested through cultural safety. Governmentality literature argues that in neo-liberal societies and the present day, we create empowered community members, while leaving the status quo untouched (King, 2003). The argument is that we are living in a time of increasing social inequalities, decreasing government responsibilities and responsabilized citizens (King, 2003; Garland, 2000). Citizenship is not only defined for our own successes and selfish consumption in the free market, but includes our responsibility for the success of others (King, 2003). In contemporary western cultures, responsabilized citizens are responsible for others in their communities as well as themselves. However, this responsibility does not mean support for welfare programs and expressing political dissent or political demands. In fact political dissent is often defined as being “silly”, or “dangerous” (King, 2003: 304):

In the present moment, conflict and dissent are typically portrayed by the mainstream media as passions that are dangerous and destabilizing. By focusing on the most disorderly performances of resistance, the media casts public activism on both the left and the right as naïve, ridiculous, shallow, and juvenile. Protest has become, to paraphrase Berlant, doubly humiliated, both silly and dangerous. It subtracts personhood from activists, making their gestures of citizenship seem proof that their very claims are illegitimate (King, 2003: 304).

Responsibilization is about being self-successful and volunteering time and money to assist the success of others. There is a certain type of inclusion and exclusion practices through this type of citizenry that is linked to breast cancer and this study.

Breast cancer has become one of the most favourite charitable causes for corporations (Davidson, 1997; Goldman, 1997). Literature here defines ‘races for the cure’, for example, as flourishing and a way that citizens are told that they are contributing to their communities, assisting the well-being of others. King (2003) uses these races as an example of changing definitions of citizenship and political inaction: “a fundraising venture, a marketing enterprise, a practice and site of consumption, a physical activity, a collective experience, a mass movement, and a pedagogical tool, the Race for the Cure is a technology of power, or a set of practices and discourses that has constitutive effects” (Foucault, 1979; 1980; cited in King, 2003: 296). The race shapes identities, for example, of citizens who volunteer their time and breast cancer survivors who are working towards a certain common goal. The problem is that this goal is defined not by the community, but as fundraising marketing enterprises. Dorothy talks about her community giving money to the Terry Fox run for cancer, yet shares how she feels this fails to address social determinants and needs in her community which may allow them to benefit from bio-medically funded cures. Important here is also what identity and citizenship is defined as not being. Lost is the critique of pharmaceutical profit, environmental causes of breast cancer and social determinants of health.

It is also in this context, therefore, that I provide an additional warning about empowerment politics, our photovoice research, and about the limits of simply applying a culturally safe lens. In this context, photovoice may be seen as a form of governance. Photovoice research may reinforce inequalities which worsen treatment of Aboriginal women inside and outside medicine. The governmentality literature alerts us to how empowering citizens through community based research or volunteerism may strengthen a

state that continues to disenfranchise people. By seemingly addressing the problems through increased funding into community based research (in this case) there is a claim to enhancing lives and giving voice to people on the margins. The problem is that there is no shifting of power, which therefore adds support to the status quo. The nature of Breast Cancer activism and research policy suggestions remain defined for us.

Academic environments and community based research strategies are employing empowerment community based approaches such as photovoice which promise participants, individual, social and political benefits. People are assured that they will have a voice towards creating social change. The problem is the more dominant groups define and regulate what is said, under the guise of “empowered citizenship”. Structures of dominance and inequalities are downplayed, as culture is illuminated and used to create an Other. Concepts such as culturalism instruct that culture becomes a technology of power (Fiske and Brown, 2006).

Within public dialogue between unequal participants, the more powerful hold the economic, cultural and human resources. This determines how the dialogue will proceed. In photovoice research, well-intentioned community advocates are offered connections to the women. These advocates use the pictures to raise awareness and continue to seek funding through mainstream cancer agencies. Mainstream solutions, however, tend to remain at the therapeutic and relational level, addressing individual needs, or cultural needs. Academic funding structures means that well-meaning academics and graduate students are not funded over long periods to continue longer term advocate work, which may address more structural changes. Institutional demands further mean that academics move on to address new research areas and acquire further research funding, often leaving

community development to the community. This means that nothing may really change for the VBC women. They may lose the opportunity to take their environmental, social and political concerns further. When empowerment politics and photovoice research are presented as a remedy, effort is not given to changing power relations between patients and providers or between citizens and government.

8.4 Conclusion: Hey, what about us? I think we are special people, not more than anybody else, but...

The VBC research seeks to address how cancer is more than individual qualities, cultural sensitivities and biomedical concerns. The participants have created individual, relational, historical, social and political analysis. Their words raise deeper questions about how citizens are defined, relationship within communities upheld, relationships of power, obligations and responsibilities of societies to individuals.

The women's voices and pictures symbolize: 1. psychological and physical experiences and needs related to survivorship including: fear, pain, resiliency, hope, strength, identity; 2. support and support experiences and needs including the importance of; family, cross-cultural understandings, diversity, traditional medicine and spirituality; 3. links to broader, structural issues including: experiences of systemic racism, colonial histories, structural inequalities, environmental and social determinants related to health. They have discussed concerns that are related to being women, Aboriginal women, rural women, working women, unemployed women, women on welfare, living on reserve and off-reserve, teachers, counsellors, community leaders, anti-racists, Pipe-carriers, Elders, healers, mothers, partners, wives, artists, farmers, trappers and more. My question is: What needs to be done so that these images and words are not decontextualized, racialized,

culturalized and used to discredit Aboriginal women, especially in health care? The flip side is that the stories are not shared. This is not a solution the women want to consider. Alternatively, only the positive experiences within the health care environment and positive experiences of their strength and resilience would be shared, but the women do not want to miss sharing the worse stories—examples of racism, examples of continued oppression through colonization and neo-colonial ideologies embedded in structures.

The women in this study may benefit from increased support, Native Liason workers and their involvement in an Aboriginal advisory committee developed through connections with well-intentioned community advocates. The photovoice display and information gained may provide more inclusive materials which recognize spiritual customs, traditional medicine, cultural and regional heterogeneity and anecdotal stories of survivors. My concern is that this work and the voices of the pictures will stop there. The women address the links between racism, socio-economic inequalities, environmental concerns and the impact of colonial policies to illness and health inequalities. Their support needs, survivorship stories and resiliency were deepened upon consideration of the intersection of gender, race, age, class and culture. We cannot define race, age, gender as an important determinant of health without also acknowledging the intersection of all of these social spaces, their impact on people's lives and heterogeneous/diverse ways of coping, survival and living.

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. A political economy lens means that corporations be challenged for promoting health services in the

interest of profit over community health. A governmentality lens means that we provide a critique of the dissent of the radical citizen and continue to voice how citizenship is part of social control.

In the end my dissertation and the talk that results from the pictures on Aboriginal women's health issues, must not privilege cultural difference, but name relationships of economic disparities and power relations linked to health and address them. This study should not contribute to an Othering of Aboriginal peoples, linking lifestyle to cultural differences. Rather, we should aim to raise awareness, celebrate diversity and address what are the most important underlying structural problems concerning all communities.

*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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APPENDIX A: RECRUITMENT MATERIALS NEWS ARTICLE BY: C. BROOKS

22

Eagle Feather
NEWS

Aboriginal breast cancer survivors are invited to share their stories

Rosemary talks about her sister's experience with breast cancer: "...my sister, Ni, she could not even say the word cancer, she would only say the c word, the c word, and she would whisper, eh. She could not bring herself to say cancer and yet she died from it".

Canadian women have a one in eight chance of being diagnosed with breast cancer. For Aboriginal women the number is higher. Yet, as a community, we are often speechless and uninformed.

The First Nations Cancer Care workshop reports that cancer rates among Aboriginal people, while historically low, are increasing dramatically for some cancers in some regions. They reported also that survival rates are lower in Aboriginal populations compared to non-Aboriginal populations. This is especially evident in breast cancer in Saskatchewan.

Little is known about what resources are available to Aboriginal breast cancer survivors, or what support might be helpful. Identifying Aboriginal women's concerns from their own words may improve knowledge and cancer care.

To this end, Jennifer Poudrier and Roanne Thomas-MacLean are seeking Aboriginal women participants who are breast cancer survivors, willing to share their voices.

While the goal is to learn from the voices of Aboriginal women survivors, most importantly, we want Aboriginal women to retain ownership of how their stories are understood.

To this end, Poudrier and Thomas-MacLean are using a new method for greater participant control over what is shared.

It is often said: "A Picture is worth

a Thousand Words". This study invites participants to take photographs which represent aspects of their survivorship that they choose to explore. Telling the story behind the photograph the women may describe their needs and lives from their point of view.

One woman said of her experience in similar photo research: "When I was first exposed to the photo project, I wasn't sure how to react ... giving me a camera and setting me loose on the city did not seem a recipe for success. I soon realized that it was a great way to let people see a window into my world."

At the end of the project she revealed: "Looking back at the photo project I feel proud because it did provide a view from the inside ... I hope that if others view my pictures, they will think, 'you know, this woman is just like me.'"

This method gives a voice to community members to communicate needs to policymakers – the pictures and words of Aboriginal women with breast cancer may increase understanding and improve cancer care.

If you are a survivor of breast cancer and are interested in participating (or if you know someone who may be interested) please call Carolyn at 220-0266.

Participants do not need any experience with photography to participate -- cameras and instruction are provided. All of the photographs will belong to and be returned to participants with an album for keepsake.

This research is supported by the Canadian Breast Cancer Research Alliance and the Department of Sociology, University of Saskatchewan



APPENDIX A: RECRUITMENT MATERIALS
NEWS ARTICLE BY: M. CAMPBELL

NOVEMBER 2005

Eagle
News

5

We need to share information about breast cancer

How do women who do not speak English communicate about their illness?

This question was asked by an elderly Cree woman while sharing her experiences with breast cancer.

Her words brought memories of my 97-year-old kokoom who passed away several years ago. She had come to spend a month with me and on this particular morning I was going to take her to Eaton's to buy a new dress for a great grandchild's wedding.

I was finishing the breakfast dishes while she took her bath when she called me in to help her. I stopped mid-way into the bathroom.

The facecloth she was holding in front of her had slipped away. She was breastless, covered with thick ugly scar tissue and around the place where her breasts had been were what looked like huge black stitches.

"Oh my god kokoom, what happened? I was horrified. She grabbed the cloth and held it in front of her.

"The doctor cut them off a long time ago," she said. "I went to the hospital and after a few days they took me to this room and gave me a needle, when I woke up the first one

Three years later she got sick again and went back to the same hospital and the other breast was removed.

Sensing my guilt she explained that she didn't call us because she didn't want to bother anyone and that my uncle who looked after her was away working.

said, "but it was still very hard because I'm not a woman anymore not even an old lady. I'm just nothing."

I remember she laughed as she said this but even today my eyes fill with tears at the memory of the pain in her voice. Recently I spent time with

cancers in some regions.

The report also states that survival rates are lower for Aboriginal populations compared to non-Aboriginal populations and this is especially evident in breast cancer in Saskatchewan.

I've lost friends and close relatives to this awful disease but I didn't realize the death rates were so high. I guess it's because as families we become isolated when someone is ill or even dying from cancer, however we do need to ask ourselves why we as Aboriginal people are so silent and uninformed about this disease we know very little about what resources are available to us and in particular to women who have been diagnosed with breast cancer.

We need to change that by doing all we can to make sure information and resources are available to our people which is what Carolyn Brooks is trying to do.

Working with two other women, they are inviting Aboriginal women who are breast cancer survivors to share their stories with the community.

These stories are important and can help other people as well as improve cancer care.

I invite you to call Carolyn at 306-926-1234 ext 2000.

Reflections

Maria Campbell



Then later she said she was too ashamed to tell him because "it was woman's stuff and she didn't want him to get mad at the doctor."

My kokoom didn't speak English and so she didn't understand what was happening until she asked a Native cleaning woman at the hospital to speak to the doctor who told her she had breast cancer and that it was a good thing she was old and didn't need her breast anymore.

Carolyn Brooks, the co-ordinator of a project called "Visualizing Breast Cancer: Exploring Aboriginal Women's Experience".

Carolyn told me that Canadian women have a one in eight chance of being diagnosed with breast cancer and for Aboriginal women the number is even higher.

She said that according to a First Nations cancer care workshop report, cancer rates among Aboriginal peoples, while historically low

APPENDIX A: RECRUITMENT MATERIALS NEWS ARTICLE BY: J. FRENCH

Monday, October 31, 2005

Saskatoon, Saskatchewan

The StarPhoenix

LOCAL A7

Digital photo project seeks insight into aboriginal breast cancer survivors

By Janet French
of The StarPhoenix

A University of Saskatchewan study hopes aboriginal women will open a window into their experiences of surviving breast cancer from behind the lens of a digital camera.

Sociology researchers are looking for breast cancer survivors who are willing to carry around a camera to show the world through their eyes.

"What we're doing is asking aboriginal women who've had breast cancer to share their stories with us," says Roanne Thomas-MacLean, an assistant professor in sociology at the university.

The experiences of breast cancer survivors who have finished their course of treatment haven't been well-studied, she said, and that's an area researchers hope to shed light on with their project, called Visualizing Breast Cancer: Exploring aboriginal women's experiences.

"There are a number of effects of treatment," Thomas-MacLean said. "Women may have difficulty returning to work. They may have difficulty with child care, grandchild care."

Her colleague, sociology assistant Prof. Jennifer Poudrier, said it's important to examine women's experiences once they leave chemotherapy and radiation behind because a person's health is determined by her surroundings.

"I guess one could argue that health is a lot more than just as it exists in your physical body," she said.

Although aboriginal women have previously had a lower incidence of breast cancer than non-aboriginals, the rate of the disease among aboriginal women has now caught up and exceeded that of non-aboriginals, project co-ordinator Carolyn Brooks said.

It's also important to look at an aboriginal woman's experience because they're less likely to survive the disease, she added.

Putting women in charge of the camera to take pictures of their life is also empowering, Poudrier said.

"Historically speaking . . . pictures were taken of aboriginal

people as something different and exotic," she said. "There's been a lot of reaction to that.

"The idea here is that we don't have a picture of an aboriginal woman with breast cancer," she said. "We have a picture of the world outside from her point of view."

Although five women have signed up for the project so far, the researchers have yet to see any of the pictures.

In a similar study of young, single mothers, women took pictures of buses, to emphasize their reliance on public transit, and cereal boxes because cereal was a nutritious and filling food mothers could feed their children while they waited empty-handed for their next paycheque, Thomas-MacLean said.

When the women return with their pictures, Brooks will interview them about the significance of their photographs. The researchers, in collaboration with the Indigenous People's Research Centre and the Breast Health Centre, hope to gather all of the study's participants in a group at the end so they can decide what they should do with the pictures.

Poudrier said one possibility is to assemble their pictures and stories into an art exhibit.

The women she's met so far are intent on using their experiences to help other women, Brooks said. One woman said she wants to make a video of herself to give to other aboriginal women with breast cancer who may not have a mentor to turn to.

"These women are incredibly excited about this study," Brooks said. "They're participating mostly just to tell their stories."

It will be up to the participating women what happens to the photos they've gathered, she said.

The project, which is funded by the Canadian Breast Cancer Research Alliance, is looking for at least seven more women to participate.

Interested women can call 220-0266 for more information.

"A lot of times women don't get to tell their story from time of diagnosis to present day," Thomas-MacLean said. "Family and friends just capture bits of the story. It's also an opportunity for women to help other women."

**APPENDIX A: RECRUITMENT MATERIALS
COMMUNITY RECRUITMENT LETTER, EXAMPLE**

To: White Buffalo Youth Lodge
Date: September 22nd, 2005

Dear White Buffalo Youth Lodge,

I would like to introduce myself to you as the project coordinator for a study on Aboriginal Women's experience of Breast Cancer. I spoke to a staff member on the phone at your agency, who recommended that I write to you and put together a package of information for you.

We are doing a study about Aboriginal women's experiences, supported by the Breast Cancer Research Alliance and the U of S. We are seeking Aboriginal women who are willing to share their experiences through one on one interview, photography and a group discussion. The hope is that identifying Aboriginal women's experience with cancer, from their own words and lives, may improve understanding and assist cancer care.

What I am asking of you is whether you may be willing to support our research by displaying posters or by giving postcards and/or information to anyone that may be interested in participating. I have included a couple of posters, a few postcards and information sheets for your perusal. I have also included a newspaper article I wrote about the study, which contains more specific details regarding the project.

I want to thank you sincerely, in advance, for looking over our information. The hope is that this information from the study will provide information on the meaning of survivorship from the perspective of Aboriginal women—with the intention of recognizing future (and present) needs. The results of this study will be disseminated widely and are intended to assist in a larger study to address the experiences of rural and remote Aboriginal women. The participants will receive an honorarium for participation and have any expenses covered.

I am looking forward to hearing from you at your convenience.

Kind regards,

Carolyn M. Brooks

**APPENDIX A: RECRUITMENT MATERIALS
RECRUITMENT POSTER**



Visualizing Breast Cancer

Exploring Aboriginal Women's Experiences

**AN INVITATION TO PARTICIPATE
IN RESEARCH ABOUT PERSONAL EXPERIENCES WITH
BREAST CANCER**



WE ARE SEEKING:

ABORIGINAL WOMEN WHO ARE BREAST CANCER SURVIVORS

LIVING IN SASKATOON

WHY?

To learn from women's own words, artistry and experiences

With the hope that the information shared may lead to future benefits for other women who experience breast cancer

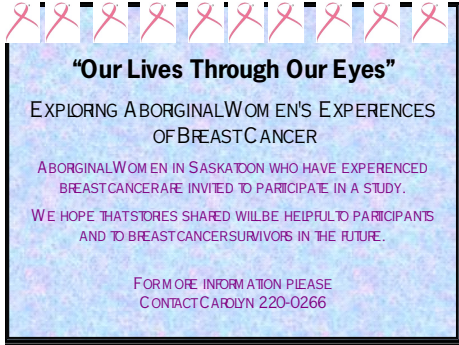
If you (or someone you know) may like to participate,
please contact: Carolyn Brooks (306) 220-0266

*You are under no obligation to participate if you call

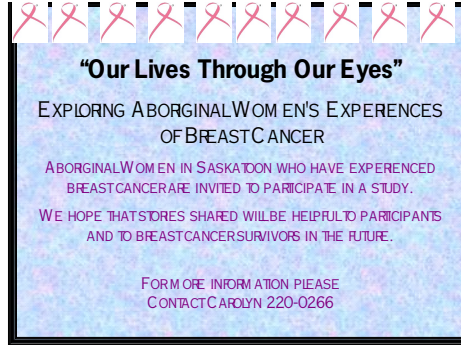
*This research is supported by the Canadian Breast Cancer Research Alliance

APPENDIX A: RECRUITMENT MATERIALS

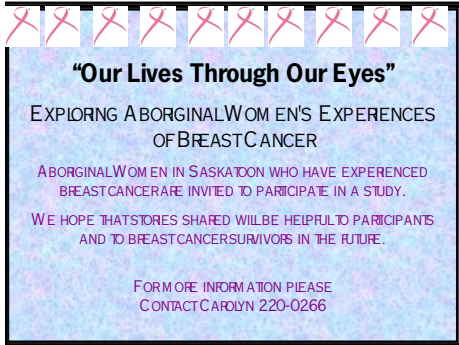
RECRUITMENT MAGNETS



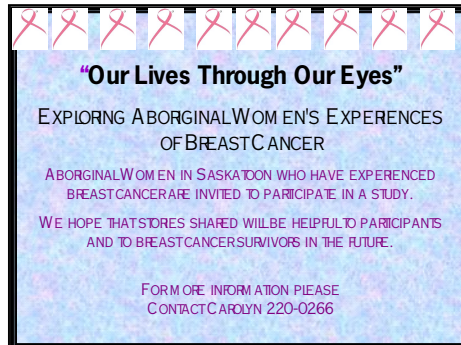
“Our Lives Through Our Eyes”
EXPLORING ABORIGINAL WOMEN'S EXPERIENCES
OF BREAST CANCER
ABORIGINAL WOMEN IN SASKATOON WHO HAVE EXPERIENCED
BREAST CANCER ARE INVITED TO PARTICIPATE IN A STUDY.
WE HOPE THAT STORES SHARED WILL BE HELPFUL TO PARTICIPANTS
AND TO BREAST CANCER SURVIVORS IN THE FUTURE.
FOR MORE INFORMATION PLEASE
CONTACT CAROLYN 220-0266



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**APPENDIX A: RECRUITMENT MATERIALS
INFORMATION SHEET**

**Information Sheet
(To be distributed to potential participants)**

**VISUALIZING BREAST CANCER:
EXPLORING ABORIGINAL WOMEN'S EXPERIENCES**

Thank you for your interest in our study.

We are doing this study to learn about Aboriginal women's experiences of breast cancer.

If you decide to participate in this study, you will be asked to:

- 1) Participate in a group discussion about breast cancer. We will also teach you how to use a digital camera at this time.
- 2) Take pictures of what breast cancer means to you. We will develop these pictures for you and you will receive a copy of your photos which you may keep.
- 3) Talk about these pictures in a one-on-one interview.
- 4) Talk about your pictures and experiences in a group discussion.

You will receive \$75.00 for participating in this study.

You may leave the study at any time if you change your mind about participating. If you decide to leave the study, we will not use any information you have shared with us.

There are no direct health benefits from this study, but we hope that the information you might share will help other women who have had breast cancer.

For more information, please contact:
Carolyn Brooks
220-0266

APPENDIX A: RECRUITMENT MATERIALS RECRUITMENT NEWS ADVERTISEMENT



The Department of Sociology **INVITES ABORIGINAL WOMEN WHO**

ARE BREAST CANCER SURVIVORS to participate in a study entitled: Visualizing Breast Cancer: Exploring Aboriginal Women's Experiences. We are seeking Aboriginal women who are willing to share their experience with the hope that the information gathered may lead to future benefits for other women who experience breast cancer. For further information, please contact 220-0266.

APPENDIX B: INTERVIEW GUIDES FOCUS GROUP GUIDING QUESTIONS

1 Orientation Group Discussion

Explanation and overview of study

Information about consent forms, confidentiality + consents for people in photos (take about 10 copies for each participant)

Signing of consent forms

Round-robin introductions

Introduction to Digital Photography (30 minutes):

Carolyn will explain how the digital cameras work and provide each participant with a copy of the manual. She will provide an example of this data collection technique and discuss her photos with participants.

Questions for Discussion (1-2 hours, depending on number of participants):

1. We (I) would like you to begin with a brief summary of your experiences with breast cancer, sharing with us when you were diagnosed and what types of treatments you received.
2. Would you please talk about your experiences with breast cancer and the impact it has had upon your life and daily routines?
Follow up questions:
 - Physical effects?
 - Disruption of regular routines?
 - Sleeping patterns?
 - Work?
 - Hobbies and sports?
 - Child care?
 - Relationship with partner?

3. Where did you get information about breast cancer? What information do you think should be available to Aboriginal women with breast cancer?
4. If participants have not talked about meanings of breast cancer, ask about what breast cancer has meant to them and to their families.
Follow up question: *Have you drawn upon Aboriginal knowledge or culture since having breast cancer?*
5. Is there something concerning breast cancer that you would like to share with us and we have not discussed?

**APPENDIX B: INTERVIEW GUIDES
PHOTOVOICE INTERVIEW GUIDE**

Interview Guide

10 February 2006

Interview Guide:

Interviewer to describe the purpose of the in-depth interviews: (ie: to collect the detailed information about their experience as an Aboriginal woman survivor of breast cancer—to get detailed information about each picture and how this reflects their experience as a survivor.) Explain that interview will first move through some questions, then participant will be asked to talk about the photos.

Sociodemographic Sheet:

Age (birth date), marital status, number of children, grandchildren,

Education

Employment

How self identify

When were you diagnosed with breast cancer?

What types of treatment did you have for breast cancer?

Questions:

- 1. If we have not recorded their experience of breast cancer from the beginning of diagnosis until the present day, we will ask the women to share these stories.**
- 2. Can you tell me what community you are from? Have you lived there your whole life? What community do you associate with the most**
- 3. Can you describe the impact of breast cancer on your everyday life? (prompts: family, friends, work, personal habits—social, physical, spiritual, cultural)
OR, interviewer can draw upon first interview to ask for more detail about particular experiences**
- 4. I see from the sheet that you self identify your Aboriginal ancestry as _____?
(prompts: Cree, Salteaux, Metis, Inuit, Blackfoot, Ojibwa, Dene,)
Has your cultural background had an impact on your experience of breast cancer? If so, could you please describe that for me?**

**(prompts: What is the meaning of breast cancer to you as an Aboriginal woman?
Are there specific qualities that you identify with from your cultural background?
Symbols that come from your Aboriginal ancestry or spiritual connections?)**

OR, interviewer can draw upon the first interview (if recorded), i.e., in your first interview, you mentioned....could you please tell me more about that?

5. Did you draw upon your cultural background through your experience of breast cancer and as a survivor? (prompts: traditional healing methods, diagnosis, self diagnosis)
If so, ask participant to explain
If not, is there a reason why not that she would care to share?
6. Could you please comment on your experiences with doctor's and nurses?
7. What would serve your needs and those of other Aboriginal women newly diagnosed?
8. Is there anything else you would like to share about your experiences before we move on to the photos you have taken?
9. We'd like to know about all of the pictures you have taken, but we'd also like to know about the ones which are the most important or meaningful to you. Could you please start by telling me about all of the pictures (or the collection as a whole)?
10. Which pictures are the most important to you?

Prompts: What are the pictures that you most identify with?
What are the pictures that tell the most about what this experience has meant to you?
Why did you take this picture?
Ask for more details about what is in pictures.
Was there anything you would have liked to photograph that you were unable to?
Which photos would you most like to share with other Aboriginal women?
Why these ones?
Are there any you would prefer not to share with other people?
What did you think of this process? Is there anything we could do differently?

Interviewer should ensure consent forms for people in photos (other than participants) are signed.

SOCIODEMOGRAPHIC INFORMATION

NAME: _____

Age (birth date): _____

Marital status: _____

Number of children: _____

Number of grandchildren: _____

Education: _____

Employment: _____

How do you self identify your Aboriginal ancestry: _____

When were you diagnosed with breast cancer?: _____

What types of treatment did you have for breast cancer?

Have you had more than one experience with cancer? If so, could you briefly explain. _____

Have any other members of your family had their own experience with breast cancer? Could you briefly explain.

APPENDIX C: CONSENT FORMS

CONSENT FORM – FOCUS GROUP DISCUSSIONS

*You are invited to participate in a study:
Visualizing Breast Cancer: Exploring Aboriginal Women's Experiences.
Please read this form carefully, and feel free to ask questions you might have.*

Researchers: Dr. Jennifer Poudrier
Department of Sociology
966-1793

Dr. Roanne Thomas-MacLean
Department of Sociology
966-1489

Purpose and Procedure: We are doing a study to learn about Aboriginal women's experiences with breast cancer. Our research questions are:

- (1) What are the experiences of Aboriginal women who have had breast cancer?
- (2) How might photographs help people to understand these experiences?

This study will last about one year in total. The orientation discussion is the first part of this study. At this time, we will also teach you how to use a digital camera. This first group discussion will take approximately two hours. The information from this group discussion will also help us to create interview questions. The interview is scheduled for approximately two hours. The second focus group discussion will take place after you have been interviewed. At this group discussion, we will talk about your experiences with breast cancer and the pictures you have taken. The final group discussion will involve approximately four hours.

Potential Risks & Benefits: There are no known risks associated with this study.

There are no direct benefits to participating in this study. We hope that the information shared will benefit other women with breast cancer. The results of this study will be shared with the Breast Health Centre and with health care professionals in Saskatoon.

You may choose to release all photographs which will be used for focus group discussion, analysis, educational and/or academic purposes (complete release) OR you may choose to release photographs only to the research assistant, Jennifer Poudrier and Roanne Thomas-MacLean (partial release). If you photograph another person then that person must also sign a release form.

Audiotapes, transcripts and photographs will be stored in a locked filing cabinet in the researchers' offices. Data will be destroyed ten years after study completion.

You will receive a copy of your photographs that you may keep.

Confidentiality: Jennifer Poudrier, Roanne Thomas-MacLean and Carolyn Brooks will keep confidential all information arising in discussion with you and in group discussions. All women in the groups are expected to keep all information confidential. The researchers will undertake to safeguard the confidentiality of the discussion, but please be aware that others may not respect your confidentiality.

The group discussions will be audiotaped. The tapes will be transcribed. Only the research team members will listen to the tapes and read the transcripts. Tapes and transcripts will be stored in a locked filing cabinet.

Your name, or the name of your community, will not appear in any report, conference presentation or publication about this study. Direct quotations from the focus group discussion may be used in publications, but transcripts and quotations will not include the names of participants. Any material used in publications will have any identifying information altered or deleted (e.g., name of your community, names of relatives, names of health care professionals) prior to publication. Although the data from this study will be published and presented at conferences, you will be assigned a pseudonym. The consent forms will be stored separately from the transcripts and photographs, so that it will not be possible to associate a name with any given set of responses.

Right to Withdraw: *You may withdraw from the study for any reason, at any time, without penalty of any sort and without loss of the honourarium. If you withdraw from the study at any time, any data that you have contributed will be destroyed.*

Before you participate in each stage of the research process, we will ask you if you are still interested in participating.

You do not have to answer any questions you do not wish to answer.

Questions: *If you have any questions concerning the study, please feel free to ask at any point; you are also free to contact the researchers at the numbers provided above if you have questions at a later time. This study has been approved on ethical grounds by the University of Saskatchewan Behavioural Sciences Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Office of Research Services (966-2084). Out of town participants may call collect. You will receive a report of the results of the study and the results will be shared at the second focus group discussion.*

If you would like more information about breast cancer or emotional support, please contact the Saskatoon Cancer Centre at 655-2662.

Consent to Participate: *I have read and understood the description provided above; I have been provided with an opportunity to ask questions and my questions have been answered satisfactorily. I consent to participate in the study described above, understanding that I may withdraw this consent at any time. A copy of this consent form has been given to me for my records.*

(Signature of Participant)

(Date)

(Signature of Researcher)

APPENDIX C: CONSENT FORMS

CONSENT FORM – INTERVIEWS

*You are being invited to participate in the next part of our study:
Visualizing Breast Cancer: Exploring Aboriginal Women's Experiences.
Please read this form carefully, and feel free to ask questions you might have.*

Researchers: Dr. Jennifer Poudrier
Department of Sociology
966-1793

Dr. Roanne Thomas-MacLean
Department of Sociology
966-1489

Purpose and Procedure: We are doing a study to learn about Aboriginal women's experiences with breast cancer. Our research questions are:

- (1) What are the experiences of Aboriginal women who have had breast cancer?
- (2) How might photographs help people to understand these experiences?

Thank you for participating in this study and for taking photographs of your experiences. The next part of this study involves an interview. The interview and your photographs will help us to learn more about your experiences. The interview will last about two hours. About one week after the interview, our research assistant will call you in case you have any questions about the project.

Potential Risks & Benefits: There are no known risks associated with this study.

There are no direct benefits to participating in this study. We hope that the information shared will benefit other women with breast cancer. The results of this study will be shared with the Breast Health Centre and with health care professionals in Saskatoon.

Audiotapes, transcripts and photographs will be stored in a locked filing cabinet in the researchers' offices. Data will be destroyed ten years after study completion.

Confidentiality: Roanne Thomas-MacLean, Jennifer Poudrier and our research assistant will keep confidential all information arising in discussion with you. The interviews will be audiotaped. The tapes will be transcribed. Only the research team members will listen to the tapes and read the transcripts.

The researchers will develop your photos for you. We will delete any photos which may identify you or other people.

Your name, or the name of your community, will not appear in any report, conference presentation or publication about this study. Direct quotations from the interview may be used in publications, but transcripts and quotations will not include the names of participants. Any material used in publications will have any identifying information

altered or deleted (e.g., name of your community, names of relatives, names of health care professionals) prior to publication. Although the data from this study will be published and presented at conferences, you will be assigned a pseudonym.

The consent forms will be stored separately from the transcripts and photographs, so that it will not be possible to associate a name with any given set of responses or photos.

Right to Withdraw: *You may withdraw from the study for any reason, at any time, without penalty of any sort and without loss of the honourarium. If you withdraw from the study at any time, any data that you have contributed will be destroyed.*

You do not have to participate in this study. Participation is completely voluntary. You do not have to answer any questions that you do not want to answer. You may stop taking pictures or end the interview at any time, if you change your mind about participating. If you decide you do not want to participate, we will not use any photographs you have taken.

Questions: *If you have any questions concerning the study, please feel free to ask at any point; you are also free to contact the researchers at the numbers provided above if you have questions at a later time. This study has been approved on ethical grounds by the University of Saskatchewan Behavioural Sciences Research Ethics Board on (insert date). Any questions regarding your rights as a participant may be addressed to that committee through the Office of Research Services (966-2084). Out of town participants may call collect. You will receive a report of the results of the study and the results will be shared at the second focus group discussion.*

If you would like more information about breast cancer or emotional support, please contact the Saskatoon Cancer Centre at 655-2662.

Consent to Participate: *I have read and understood the description provided above; I have been provided with an opportunity to ask questions and my questions have been answered satisfactorily. I consent to participate in the study described above, understanding that I may withdraw this consent at any time. A copy of this consent form has been given to me for my records.*

(Signature of Participant)

(Date)

(Signature of Researcher)

**APPENDIX C: CONSENT FORMS
TRANSCRIPT AND PHOTOGRAPH RELEASE FORMS**

TRANSCRIPT RELEASE - INTERVIEWS

The research assistant will ask participants to sign this form if they indicate they would like to review the transcript. The RA will arrange for direct delivery of the transcript and participants will be asked to sign this form when the RA picks up the transcript after it is read.

I, _____, have been offered the opportunity to review the complete transcript of my personal interview in the study: **Visualizing Breast Cancer: Exploring Aboriginal Women’s Experiences.**

I acknowledge that the transcript accurately reflects what I said in my personal interview with [name of the RA]. I hereby authorize the release of this transcript to Jennifer Poudrier and Roanne Thomas-MacLean to be used in the manner described in the consent form. I have received a copy of this Data/Transcript Release Form for my own records.

Participant

Date

Researcher

Date

APPENDIX C: CONSENT FORMS
PHOTOGRAPHS RELEASE

The research assistant will carefully explain each of the following criteria for the release of photographs prior to the signing of this form.

I, _____, have reviewed the photographs I have taken as part of the study entitled **Visualizing Breast Cancer: Exploring Aboriginal Women’s Experiences**.

I agree to the following release of my photographs:

- _____ Complete release - For analysis, educational and/or academic purposes.
- _____ Partial release to Carolyn Brooks, Jennifer Poudrier and Roanne Thomas-MacLean – For analysis and sharing at the second group discussion.

I hereby authorize the release of the photographs to Jennifer Poudrier and Roanne Thomas-MacLean to be used in the manner indicated above. I have received a copy of this Data Release Form for my own records.

Participant

Date

Researcher

Date

APPENDIX C: CONSENT FORMS REVISED CONSENT REGARDING ANONYMITY

CONSENT FORM: ANONYMITY AND CONFIDENTIALITY

To be distributed and signed at the end of the sharing circle.

In the initial consent form we have ensured that you will have complete anonymity and confidentiality. This process is designed to recognize your entitlement to privacy and right to anonymity. This form is designed to ensure that each participant has the choice to be identified or to remain anonymous. This is a recognition that some participants may not wish to be anonymous and prefer to be credited for the contributions made to this project.

Through this form you may choose whether your name, or the name of your community, will or will not appear in any report, conference presentation or publication about this study. Direct quotations from the interviews and focus group discussion may be used in publications, but transcripts and quotations may or may not include the names of participants. We are also asking about your choice for identification through the photographs you are in.

I, _____, have been offered the opportunity to reveal my identity or de-identify myself in the study **Visualizing Breast Cancer: Exploring Aboriginal Women's Experiences**.

Interviews:

_____ **I would like to be identified in the study.** Identifying information may be used (e.g., name of your community, names of relatives, names of health care professionals). **I choose to have my real name used.**

_____ I would like any material used in publications to have **identifying information altered or deleted** (e.g., name of your community, names of relatives, names of health care professionals) prior to publication. Although the data from this study will be published and presented at conferences, **I would like to be assigned a pseudonym.** The consent forms will be stored separately from the transcripts and photographs, so that it will not be possible to associate a name with any given set of responses.

Photographs:

_____ I would like photographs of myself to be used in the study and in publications.

_____ I would like my face to be de-identified in the pictures I am in for the study and in publications.

I have received a copy of this form for my own records.

Participant

Date

Researcher

Date

CURRICULUM VITAE
For
Carolyn M. Brooks
November 1, 2008

1. CONTACT INFORMATION:

Address: 413 Willow Street, Saskatoon, SK. S7J 0C7
Tel.: (306) 652-9580 or (306) 290-9218
Email: Carolyn.brooks@usask.ca

2. ACADEMIC CREDENTIALS:

2005-present: **Ph.D. Candidate, Department of Sociology**
University of Saskatchewan

1994: **M.A., Department of Sociology**
University of Saskatchewan

1988: **B.A. Honors, Department of Sociology**
University of Saskatchewan

3. AREAS OF SPECIALIZATION, TEACHING AND RESEARCH INTERESTS:

Criminology and Criminological Theory; Penology and Corrections; Violence; Youth Crime and Justice; Women, Crime and Imprisonment; Social Justice; Social Control; Methods of Social Research (Quantitative and Qualitative); Social Justice and Health Inequalities

4. HONOURS (AWARDS, FELLOWSHIPS, PRIZES):

2007-2009: **SSHRC Doctoral Award**
The Social Sciences and Humanities Research Council Doctoral Fellowship.
Amount Awarded \$40,000.00.

2006-2007: **Ph.D. Thesis Scholarship.**
Department of Sociology, College of Graduate Studies and Research, University of Saskatchewan.
Amount Awarded \$18,000.00.

2003-2004: **Sylvia Wallace Sessional Lecturer Teaching Excellence Award**
Gwenna Moss Teaching and Learning Center (GMCTE), University of Saskatchewan
Awarded \$1,000.00 from the GMCTE and travelling costs to the STLHE conference, University of Ottawa.

2002-2003: **USSU Teaching Excellence Award**

University of Saskatchewan Students' Union, University of
Saskatchewan

- 1989–1991: **Graduate Student Scholarship**
 Department of Sociology, College of Graduate Studies, University of Saskatchewan
 Awarded \$7,500.00 (1990); Awarded \$7,200.00 (1989).
- 1989–1991: **Summer Research Scholarship**
 Department of Sociology, College of Graduate Studies, University of Saskatchewan
 Awarded \$3,750.00 (1990); Amount Awarded \$3,750.00 (1991).
- 1986-1987: **Hantelman Humanities Scholarship**
 University of Saskatchewan

5. RESEARCH POSITIONS:

- Sept. 2007-present **Research Manager**
 Title: *Iskwewak Miwawaywak, Women Feeling Healthy*
 PI: Dr. Jennifer Poudrier, Sociology Department, University of Saskatchewan
 Project management, ethics, data gathering, qualitative research analysis, report and academic writing, presenting at community meetings and focus groups.
 Funded by: Canadian Institute for Health Research (CIHR)
- Jan. 2008-present: **Research Assistant**
 Title: *Negotiating Resilience: Protective Processes of Children in Transition across Cultures and Contexts*
 Local Site PI: Dr. Les Samuelson, Sociology Department, University of Saskatchewan
 China Site PI: Dr. Wenxin Zhang, Shandong Normal University, Jinan, Shandong
 Participant recruitment, ethics, data gathering—using photovoice, day in the life video compilation and qualitative interviewing in Canada and China.
 Funded by: Social Sciences and Humanities Research Council of Canada (SSHRC)
- Sept. 2005-present: **Saskatoon Site Interviewer Co-ordinator**
 Title: *The Healing Journey: Longitudinal Study of Women Affected by Partner Violence*
 PI: Dr. Jane Ursel, Department of Sociology, Resolve, University of Manitoba
 Interviewer, Interviewer co-ordinator and quantitative and qualitative research trainer for longitudinal tri-provincial data Saskatoon site.
 Funded by: Social Sciences and Humanities Research Council of Canada (SSHRC)
- Sept. 2005-2007: **Research Project Manager**
 Title: *Visualizing Breast Cancer: Exploring Aboriginal Women's Experiences of Breast Cancer*
 PIs: Dr. Roanne Thomas-MacLean and Dr. Jennifer Poudrier, Sociology Department, University of Saskatchewan
 Participant recruitment, grant proposals, academic writing and presentations, data gathering and analysis—using photovoice,

qualitative interviews and focus groups.
Funded by: Canadian Breast Cancer Research Alliance

June, 2007-Nov. 2007:

Workshop Organizer

Title: *Exploring Research Possibilities—Indigenous Peoples and Breast Cancer*

PIs: Dr. Roanne Thomas-MacLean and Dr. Jennifer Poudrier, Sociology

Department,

University of Saskatchewan.

Development of the funding proposal, bringing together key researchers and stakeholders, organization and co-facilitating.

Funded by: 1) Indigenous Peoples' Health Research Centre Partnership/Network Development Grant; 2) Saskatoon Health Region.

6. PREVIOUS TEACHING AND RELATED EMPLOYMENT:

Teaching:

1993-2007: **Sessional Lecturer, Department of Sociology, University of Saskatchewan**

Courses Taught:

- Soc 418.3 – Advanced Criminology
- Soc 329.3 – Penology and Corrections
- Soc 312.3 – Current Issues in Criminal Justice
- Soc 330.3 – Sociology of Law
- Soc 242.3 – An Introduction to the Sociology of Women and Gender Studies
- Soc 214.3 – Social Control
- Soc 212.3 – Crime and Delinquency

2000-2005: **Sessional Lecturer, Department of Sociology, St. Thomas More College**

Courses Taught:

- Soc 242.3 – An Introduction to the Sociology of Women and Gender Studies
- Soc 214.3 – Social Control
- Soc 212.3 – Crime and Delinquency

2003-2005: **Sessional Lecturer, Women's and Gender Studies, University of Saskatchewan**

Courses Taught:

- WGST 311.3: – Contemporary Feminist Thought
- WGST 350.3: – Women and Current Legal Issues
- WGST 110.6: – Introduction to Women and Gender Studies

2001-2002: **Assistant Professor, One Year Term Position, Department of Sociology, University of Saskatchewan**

Courses Taught:

- Soc 818.3 – Advanced Seminar in Criminology
- Soc 418.3 – Advanced Criminology
- Soc 212.3 – Crime and Delinquency

1992-2001: **Sessional Lecturer, St. Peter's College, Meunster, SK.**

Courses Taught:

- Soc 329.3 – Penology and Corrections
- Soc 330.3 – Sociology of Law
- Soc 214.3 – Social Control

Soc 212.3 – Crime and Delinquency
Soc 110.6 – Introduction to Sociology
WGST 110.6110.6: – Introduction to Women and Gender Studies (Interdisciplinary TEAM taught)
1994-1996: **Sessional Lecturer, Faculty of Human Justice, University of Regina**
Courses Taught:
HJ351 – Issues in Social Control

Related Employment:

- 1990-1991: **Tutor, St. Thomas More College, Saskatoon, SK.**
Course Tutored:
Soc. 233.3 – Introduction to Sociological Theory
- 1990-1991: **Tutor, Saskatoon District Tribal Council Counselling Centre, Saskatoon, SK.**
Course Tutored:
Soc. 220.6 – Social Welfare Organization
- 1992-1994: **Researcher/Writer & Volunteer Co-ordinator, Elizabeth Fry Society, Saskatoon, SK.**
- 1991-1992: **Counsellor, Counselling Co-ordinator, Elizabeth Fry Society, Kelowna, B.C.**
- 1988-1989: **Child Care Counsellor II, Maples Adolescent Treatment Center
Ministry of Health, Human Resource Div., Burnaby, B.C.**

7. BOOKS, CHAPTERS IN BOOKS, EXPOSITORY AND REVIEW ARTICLES - ACCEPTED/PUBLISHED:

Books:

Carolyn Brooks and Bernard Schissel. (editors). 2008. *Marginality and Condemnation: An Introduction to Criminology*. Halifax, NS: Fernwood Publishing, 2nd Edition, 514 pp

Bernard Schissel and **Carolyn Brooks** (editors). 2003. *Marginality and Condemnation: An Introduction to Critical Criminology*. Halifax, NS: Fernwood Publishing, 442 pp.

Chapters in Books:

Brooks, Carolyn, Jennifer Poudrier and Roanne Thomas-MacLean. 2008. "Creating Collaborative Visions with Aboriginal Women: A PhotoVoice Project". In Pranee Liamputtong (ed.). *Doing Cross-Cultural Research: Ethical and Methodological Perspectives*. Netherlands: Springer/Kluwer Publishers.

Brooks, Carolyn and Bernard Schissel. 2008. "The Application of Criminological Theory to Contemporary 'Crime' Issues." In Carolyn Brooks and Bernard Schissel. (eds), *Marginality and Condemnation: An Introduction to Criminology*. Halifax, NS: Fernwood Publishing, 2nd Edition. **New chapter**. Pp. 456-478.

Brooks, Carolyn. 2008. "The Politics of Imprisonment". In Carolyn Brooks and Bernard Schissel (eds.). *Marginality and Condemnation: An Introduction to Criminology*. Halifax: Fernwood.

Brooks, Carolyn. 2008. "Rejecting Short-term Solutions to Crime". In Carolyn Brooks and Bernard Schissel (eds.). *Marginality and Condemnation: An Introduction to Criminology*. Halifax: Fernwood.

Brooks, Carolyn. 2003. "New Directions in Critical Criminology". In Bernard Schissel and Carolyn Brooks (eds.) *Marginality and Condemnation: An Introduction to Criminology*. Halifax: Fernwood.

Brooks, Carolyn. 2003. "Globalization and a New Class of Disposable People". In Schissel, Bernard and Carolyn Brooks (eds.) *Marginality and Condemnation: An Introduction to Criminology*. Halifax: Fernwood.

Carey (Brooks), Carolyn. 1996. "Women in Prisons: The Punishment of Privation". In Bernard Schissel and Linda MaHOOD (EDS.). *Social Cotnrol in Canada: Issues in the Social Construction of Deviance*. Don Mills, Ontario: Oxford University Press.

Papers in Refereed Journals— Accepted/Published:

Roanne Thomas-MacLean, Jennifer Poudrier and **Carolyn Brooks**, *Envisioning the Future with Young Aboriginal Breast Cancer Survivors*. Atlantis: A Women's Studies Journal. In press.

Published Peer Reviewed Conference Proceedings and Abstracts:

Brooks, Carolyn, Jennifer Poudrier and Roanne Thomas-MacLean. 2008. *Visual Storytelling: Quality of Life Concerns of Aboriginal Women Breast Cancer Survivors*. Reasons for Hope Fifth Scientific Conference, Canadian Breast Cancer Research Alliance, Vancouver B.C., p. 247.

Thomas-MacLean, Roanne, Jennifer Poudrier and **Carolyn Brooks**. 2007. *What is Ethical Health Care? Words and Images from Aboriginal Breast Cancer Survivors*. Making Connections: A Canadian Cancer Research Conference Celebrating NCIC's 60th Anniversary, November 15-17, 2007, Toronto, Ontario, pp. 127.

Brooks, Carolyn, Jennifer Poudrier and Roanne Thomas-MacLean. 2007. "Our Lives through Our Eyes": *Affirming Lived Experiences and Critical Dialogue through Photovoice Research with Aboriginal Women*. Poster Session Highlighting Aboriginal Research at the University of Saskatchewan, May 26-June 2, Saskatoon, SK. P. 12.

Brooks, Carolyn. 2007. *Situated Activism: Visual Narratives of Saskatchewan Aboriginal Breast Cancer Survivors*". Congress of Humanities and Social Sciences, May-June 2007, University of Saskatchewan. P.

Thomas-MacLean, Roanne, Jennifer Poudrier and **Carolyn Brooks**. 2006. *Photography as Empowering for Aboriginal Breast Cancer Survivors: Suggestions for Primary Health Care*. 34th Annual North American Primary Health Care Conference, Tucson, AZ. P. 202.

Thomas-MacLean, Roanne, Jennifer Poudrier and **Carolyn Brooks**. 2006. *Empowering Images: Aboriginal Women's Voices and Photos*. Reasons for Hope Fourth Scientific Conference, Canadian Breast Cancer Research Alliance, Montreal PQ, p. 247.

Brooks, Carolyn, Jennifer Poudrier and Roanne Thomas-MacLean. 2005. *Visualizing Breast Cancer: Exploring Aboriginal Women's Experiences*. 5th Annual Saskatchewan Cancer Research Day, December 8, Saskatoon SK. Pp. 18-19.

Technical Reports Prepared Relevant to Academic Field:

2008. *Multiple Exposures: An Environmental Scan of Miwayawin Health Services regarding healthy body weight and body image*. Prepared for the Research Project entitled: Iskwewak Miwayawak Women Feeling Healthy. PI. Dr. Jennifer Poudrier. Funded by: Canadian Institute for Health Research (CIHR)

Carey (Brooks), Carolyn. 1992. *Women in Conflict with the Law*. Prepared for the Elizabeth Fry Society of Saskatchewan Intermediary Education Project. Funded by: Public Legal Education and Information Special Projects Fund, Department of Justice, Canada.

Carey (Brooks), Carolyn. 1992. *Aboriginal Women in Conflict with the Law*. Prepared for the Elizabeth Fry Society of Saskatchewan Intermediary Education Project. Funded by: Public Legal Education and Information Special Projects Fund, Department of Justice, Canada.

Carey (Brooks), Carolyn. 1992. *Young Female Offenders*. Prepared for the Elizabeth Fry Society of Saskatchewan Intermediary Education Project. Funded by: Public Legal Education and Information Special Projects Fund, Department of Justice, Canada.

Carey (Brooks), Carolyn. 1992. Prepared for the Elizabeth Fry Society of Saskatchewan Intermediary Education Project. Funded by: Public Legal Education and Information Special Projects Fund, Department of Justice, Canada.

8. PRESENTATIONS AT CONFERENCES:

Jennifer Poudrier, Roanne Thomas-MacLean and **Carolyn Brooks**. 2007. *Moving Forward: Learning from Aboriginal Breast Cancer Survivors' Photography*. Cancer Research Day, Saskatoon SK December 5, 2007.

Carolyn Brooks. 2007. *Situated Activism: Visual Narratives of Saskatchewan Aboriginal Breast Cancer Survivors*. Congress of Humanities and Social Sciences, May-June 2007, University of Saskatchewan. P.

Carolyn Brooks, Jennifer Poudrier and Roanne Thomas-MacLean. 2007. "Our Lives through Our Eyes": *Affirming Lived Experiences and Critical Dialogue through Photovoice Research with Aboriginal Women*. Poster Session Highlighting Aboriginal Research at the University of Saskatchewan, May 26-June 2, Saskatoon, SK. P. 12.

Carolyn Brooks. Discussant for Session entitled: *The Marginalization of Children and Youth: A Human Rights Issue*. Congress of Humanities and Social Sciences, May-June 2007, University of Saskatchewan. P.

Roanne Thomas-MacLean, Jennifer Poudrier and **Carolyn Brooks**. 2006. *Photography as Empowering for Aboriginal Breast Cancer Survivors: Suggestions for Primary Health Care*. 34th Annual North American Primary Health Care Conference, Tucson, AZ, p. 202.

Roanne Thomas-MacLean, Jennifer Poudrier and **Carolyn Brooks**. 2006. *Empowering Images: Aboriginal Women's Voices and Photos*. Reasons for Hope Fourth Scientific Conference, Canadian Breast Cancer Research Alliance, Montreal PQ, p. 247.

Carolyn Brooks, Jennifer Poudrier and Roanne Thomas-MacLean. 2005. *Visualizing Breast Cancer: Exploring Aboriginal Women's Experiences*. 5th Annual Saskatchewan Cancer Research Day, December 8, Saskatoon SK. Pp. 18-19.

Carolyn Carey (Brooks). 1994. *Women, Crime and Criminal Justice*. Presidential Lecture Series. St. Peter's College, Meunster, Saskatchewan.

Carolyn Carey (Brooks). 1992. *The Treatment and Punishment of Federally Sentenced Women in Canada: A Critical Legal History*. Changing the Climate: Graduate Studies and Research, University of Saskatchewan.

Carolyn Brooks. 1991. *The Prison for Women in Kingston and Decentralization: A Critical History.* The Annual Meeting of the Canadian Association of Sociology and Anthropology, Queen's University, Kingston Ontario.

9. INVITED UNIVERSITY AND COMMUNITY PRESENTATIONS/ CONTRIBUTIONS – UNIVERSITY RELATED:

Presenter, "Photovoice as a research tool for *Iskwewak Miwawaywak, Women Feeling Healthy*," Community Stakeholders Meeting with Band Chiefs, Health Portfolio Councilors from Battelford Tribal Councils Communities, 2008.

Lecturer, "Epistemology and Methodologies: Anti-Oppressive Paradigms and Visual Research Methods," Sociology 332.6 (Dr. Susan Robertson), Principles of Research Design, 2007.

Lecturer, "Visual Methods and Photovoice Research with Indigenous Peoples," Sociology 841.3 (Dr. Roanne Thomas-MacLean), Advanced Methods, 2007.

Lecturer, "Indigenous Peoples and Health Research," Sociology 398.3 (Dr. Elizabeth Quinlin), Social Inequality and Health, 2006.

Lecturer, "Visualizing Breast Cancer: Exploring Aboriginal Women's Experiences using Photography," Sociology 398.3 (Dr. Roanne Thomas-MacLean), Social Inequality and Health, 2006.

Lecturer, "Indigenous Peoples and Health Research," Sociology 238.3 (Dr. Jennifer Poudrier), Sociology of Health: Illness and Health, 2006.

Presenter, "Visualizing Breast Cancer: Exploring Aboriginal Women's Experiences through Photography," First Nations University, 2005.

Presentation towards recruitment, "The Healing Journey: Longitudinal Research on Women Affected by Intimate Partner Violence," Saskatoon Community Training Residence, 2005.

Presentation towards recruitment, "The Healing Journey: Longitudinal Research on Women Affected by Intimate Partner Violence," Family Service Saskatoon Abuse Groups, 2005.

Presenter, "Youth Crime, Moral Panics and the Law," First Nations University, 2004.

Presenter/Organizer, "The Roles and Experiences of a Sessional Lecturer," Gwenna Moss Center for Teaching Effectiveness Workshop Series, 2004.

10. NEWS INTERVIEWS AND STORIES:

Star Phoenix interview with Dr. Stephanie Martin for the research project entitled: *The Healing Journey*, published Thursday, December 22nd, 2005.

Star Phoenix interview with Dr. Jennifer Poudrier and Dr. Roanne Thomas-MacLean for the research project entitled: *Visualizing Breast Cancer*, published Monday, October 31st, 2005. Article Title: *Digital photo project seeks insight into Aboriginal breast cancer survivors*.

Wrote an article for Eagle Feather News about the research project entitled: *Visualizing Breast Cancer*, published in October, 2005. Article Title: *Aboriginal breast cancer survivors are invited to share their stories*.

Eagle Feather News interview with Elder Maria Campbell about the research project entitled: *Visualizing Breast Cancer*, published November, 2005. Article Title: *We need to share information about breast cancer.*

11. DEPARTMENTAL AND COLLEGE COMMITTEES:

Department of Sociology, University of Saskatchewan

Teaching Committee, Chair, 2001-2002

Teaching Committee, 1993, 1998-2005

Additional Membership Roles (Teaching Focused), Department of Sociology, University of Saskatchewan

Co-presenter/co-organizer of a series of workshops on "Teaching Sociology" including: Group Process Learning; and Teaching Students to Write, 2001-2002.

Co-presenter/co-organizer of a series of workshops on "Teaching Sociology" including: Lecture Preparation; Discussion Groups; The Teaching Dossier; and Incorporating the Textbook into Teaching., 1995.

St. Peter's College, Meunster, Saskatchewan

St. Peter's Faculty Association Active Member, 1992-2001

Other

Gwenna Moss Teaching and Learning Center, Sylvia Wallace Awards Committee, 2003-present

