Envisioning the Future with Aboriginal Breast Cancer Survivors

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Abstract
Photovoice is a newly emerging participatory method of research. In this article, we discuss findings resulting from a photovoice project completed with young Aboriginal women who had experienced breast cancer. Three key interrelated themes linked to ethnicity, age, and identity, were particularly salient for the research participants. These are conceptualized as: (1) shame and silence; (2) resilience and strength; and (3) support.

To date, there has been little attention paid to ethnicity and its intersection with quality of life after breast cancer, particularly with regard to psychosocial well-being. A recent literature review yielded few articles about Aboriginal women's experiences of life after breast cancer, indicating that the meaning of breast cancer has not been explored from their perspectives. There has also been very little work done in the area of young women's experiences with breast cancer. Young, Aboriginal women therefore face a situation where the lack of knowledge and attention to their experiences is compounded by factors related to ethnicity and age. In this article, we describe our exploration of their experiences through a qualitative visual research technique, photovoice.

While interviews and focus group discussions have become prevalent means of collecting qualitative data, the potential of visual methods (for example, photography) has only recently been realized. Current research suggests that photography may be a creative way to better understand the experiences of populations that have been marginalized, such as young, 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 objective of our project was to develop an understanding of the meaning of breast cancer for Aboriginal women in Saskatchewan. Although our participants ranged in age from 41 to 65, this article focuses on the experiences of a
specific sub-sample, namely young women (i.e., those in their early 40s and younger at time of diagnosis), who were involved with the Visualizing Breast Cancer project. Completion of the project involved drawing upon a number of substantive areas relevant to the topic.

Background

Three key domains provide the theoretical and methodological context for our work: Aboriginal health, qualitative studies of cancer experiences, and visual methods.

Aboriginal health and healing is a consequence of a "complex web of physiological, psychological, spiritual, historical, sociological, cultural, economic and environmental factors" (Waldram et al. 1995, 3). Aboriginal conceptions of health and healing revolve around the primary notions of holism, interconnectedness and balance, within the larger context of the community, the family and the environment (Ellerby et al. 2000). Attending to cultural and gendered contexts of wellness and experiences, as well as improving Aboriginal autonomy over health care decisions are fundamental prerequisites for bettering health among Aboriginal women (PWHCE 2004). The Royal Commission on Aboriginal Peoples' Health and Healing (RCAPHH 1996) has indicated, for many Aboriginal cultures, good health is "a state of balance and harmony involving the body, mind, emotions, and spirit" (1996, 57). Although research has shown that Aboriginal peoples suffer a disproportionate amount of physical illness, it is crucial to recognize that health for many Aboriginal people is intricately connected to experiences of wellness associated with the community, socio-economic position, identity, and tradition (Reading and Nowgesic 2002; National Aboriginal Health Organization 2002/03). Research in the area of Aboriginal women's health is increasing, yet Cecilia Benoit, Dena Carroll and Munaza Chaudhry note that "There is now a substantial body of research on Aboriginal health showing that Aboriginal women face formidable barriers in gaining access to the mainstream health care system" (Benoit et al. 2003, 830).

While Aboriginal women are not a homogenous population, Aboriginal breast cancer survivors may have different experiences of survivorship than non-Aboriginal women, with a corresponding need for different resources and types of support, given the history and continuing legacy of colonialism (Benoit et al. 2003). More alarming is work which shows that health care professionals may not be thinking critically about their own assumptions about culture and the social context of health care (Browne 2005). Therefore, identifying and describing Aboriginal women's breast cancer experiences would provide a significant contribution toward knowledge about Aboriginal conceptualizations of health, as well as encounters with the health care system. Such knowledge would also enhance prior research aimed at qualitatively understanding the impact of cancer.

A number of studies point to the complexity of both breast cancer treatment and survivorship. These suggest that psychological and sociological issues associated with breast cancer are experienced during and after treatment, as well as over the long term (i.e., longer than 5 years post-treatment) (Antoni et al. 2006; Holzner et al. 2001; Tomich and Hegelson 2004;). Further, issues related to treatment (for example, premature menopause) do not cease with the conclusion of acute care (Thomas-MacLean 2004a; 2005).

Along with recognizing the long-term impact of illness and treatment, it is also important to include diverse perspectives in developing an understanding of the psychosocial dimensions of breast cancer in order to more fully appreciate the similarities and differences between various groups of women and to begin to establish what their physical and emotional needs might be. Recent research focuses on the meaning of
the experience, possible long-term effects of illness and treatment, as well as positive aspects (Thomas-MacLean 2004 a & b; 2005; Tomich and Helgeson 2002). The lack of attention to the psychosocial dimensions of breast cancer is pronounced with respect to ethnicity (Ashing et al. 2003; Gotay et al. 2002), and those researching satisfaction with medical care assert that Aboriginal people's experiences have been neglected (Garrout et al. 2004). Researchers examining the intersection of ethnicity and breast cancer suggest that such studies are scant, but that existing research recommends that ethnicity is an important dimension of cancer experiences that needs attention (Gotay et al. 2002). Our study is framed within prior research utilizing qualitative methods, such as narrative research, to explore breast cancer experiences (Thomas-MacLean 2004 a & b; Carter 1993; Colyer 1996). Thus, our work adds to literature on psychosocial aspects of breast cancer, as well as new advances in qualitative methods, such as photography.

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 (Berg 2004; Creswell 1998 & 2003; Denzin and Lincoln 2005). Photovoice, which has connections with feminist epistemology and literatures in visual knowledge and power, is a research tool by which research participants tell their stories and assess their needs visually (Harrison 2002). Photovoice prioritizes participants' knowledge as a vital source of expertise, with "the possibility of perceiving their world from the viewpoint of the people who live lives that are different from those traditionally in control of the means for imagining the world" (Ruby 1991, 50).

Photovoice was successfully developed by Wang and Burris to enable Chinese village women to photograph their health experiences and transform their health outcomes (Wang and Burris 1997). Photovoice is currently used to empower people "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). In these ways, power inequalities may be addressed by investing participants with the authority and responsibility to define important issues in their lives, as is congruent with feminist approaches to research. Moreover, photovoice may facilitate the reclamation of indigenous knowledge, which is a critical component of health and healing for indigenous people (Moffitt and Robinson 2004). While photovoice has been used in ways congruent with our research, its use for understanding the meaning of breast cancer and Aboriginal health has not been explored in prior research.

Research Methods and Methodology

Thomas-MacLean has been working with breast cancer survivors for several years. Her background is in the sociology of health and illness and she has focused on qualitative methods. Poudrier is a Métis researcher whose research and theoretical interests examine the intersections between visual culture, studies of science and indigenous knowledge, and Aboriginal health, focusing on decolonizing methodologies. Brooks has worked with Aboriginal women in the area of justice. Thomas-MacLean and Poudrier designed the study, while Brooks was responsible for data collection. All of the team members contributed to the interpretation of the interview transcripts and photographs.

Our network of collaborators was vital to the success of the project. An Aboriginal researcher, Rose Roberts, associated with the Faculty of Nursing at the University of Saskatchewan provided guidance during the development of the study design, as did a Métis, primary care physician/researcher, Janet Smylie. A Métis Elder who wishes to remain anonymous also provided guidance during the study design and wrote a newspaper article in a
First Nations publication in support of the study. Members of breast cancer support groups also helped to publicize the study. In 1996, 55,800 women in Saskatchewan reported their identity as Aboriginal (positive responses to Census question that used the descriptors North American Indian, Métis, or Inuit). It is estimated that 610 Saskatchewan women were newly diagnosed with breast cancer in 2004 (Canadian Cancer Society 2005).

There are two major urban areas in this province: Regina and Saskatoon. They are similar in size, with populations of approximately 225,000 people. Eight participants lived in urban areas, while the remaining participants lived within a 300 kilometre range of the two major urban centres.

Articles about the study appeared in a Saskatoon newspaper as well as a First Nations newspaper. Aboriginal organizations, universities, a cancer centre and Breast Cancer Action Saskatchewan also distributed information. 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 Saskatchewan, and (5) identify as Aboriginal. Reimbursement for participation was $75 for three stages (two interviews and photography) of data collection.

Prior to beginning the study, Brooks completed a pilot test of the digital cameras and she prepared a portfolio of photographs to share with participants. The women were asked to take pictures of what breast cancer meant to them and were provided with basic written instructions for operating the cameras. Brooks described these instructions and the use of the cameras in detail during the initial interviews. She also shared a portfolio of her own photos. Each participant was asked to take as many photos as she wished, with the suggestion that 12-15 photographs would be sufficient for study purposes.

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 Brooks and the participant. Together, Brooks and the participant discussed the photos and the woman’s cancer experiences. The women then selected several photos that they felt were especially meaningful and discussed them. This second interview was also digitally recorded and the photos were saved to the laptop computer. Each of the interviews was transcribed verbatim, using a digital transcriber.

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 150 photographs. Of the 12 participants who completed the study, six were in their early 40s or younger at the time of diagnosis, and it is their stories and photos we discuss in this article.

Extensive team discussions, as well as review of the transcripts and photos guided the interpretive processes. Theoretical frameworks related to Aboriginal health and gender provided filters through which to interpret the stories and photos shared with us. With respect to understanding the women’s words and photos, our interpretations were connected to writings on Aboriginal health which recognize health not only as physiological, but as connected to sociology, history and culture (Walfram et al. 1995). Aboriginal women's health cannot be improved without attention to gender. Denise L. Spitzer notes that the "relationship between gender inequalities and health is seldom static and intersects with factors such as ethnicity, sexuality, age and disability in dynamic and complex ways" (Spitzer 2005, 78).

Additional guidance for the analysis came from various writings on photovoice and the use of visual methods in sociology. Wright
provides some guidance for reading images, suggesting that there are three processes involved: "looking through the image to information internal to it; looking at the image to examine the way in which the content is presented; and looking behind the image to examine the context, or the social and cultural relations that shape its production and interpretation" (Riley and Manias 2003, 85).

Participants also provided guidance for the interpretation of the photos as they were discussed extensively during the second interviews. Subsequently, verbatim transcripts were printed by the research team and compared to "thumbnails" of the photos. In this way, the index of photos could be compared directly to participants' stories and explanations. Initial themes emerged through this comparative approach as well as team discussions.

Finally, participants were asked to provide feedback on this research process. All of the participants expressed the idea that they benefited individually and relationally from the research. They spoke of enjoying the creative process and the attention received from media and policymakers. Relationships also developed between the participants. In words of the women: "This was a great way to tell my story;" and "This photo project was a wonderful, wonderful exercise."

Findings

Participants described their own Aboriginal identity and experiences in many ways. Aboriginal identity is not a homogenous category or concept, and aboriginality is a contested concept. Sandra, one of our participants, suggests that there are "so many First Nation's people, [with] different languages, different cultures. Although there's a lot of similarities, there's some great differences too." Likewise, as we see in the photos, there are different experiences of age, identity, ethnicity, race and cancer.

Three key interrelated themes linked to ethnicity, age, and identity were particularly salient: (1) shame and silence; (2) resilience and strength; and (3) support. The first theme relates to the shame and silence some young Aboriginal women experienced after being diagnosed with breast cancer. The second theme, resilience and strength, is discussed in specific relation to the women's experiences of ethnicity and breast cancer. The third theme discusses what participants perceive as important areas of support, including discussions of their experience of racism, economic realities and quality of care.

The theme of shame and silence captures many ideas related to silence surrounding breast cancer in some Aboriginal communities. It also captures some women's experiences of feeling exposed or vulnerable, while also feeling that they were hidden, or marginalized. Several women spoke about the stigma surrounding cancer in some Aboriginal communities. The cultural silence and fear suggest that if you speak of cancer, or check your body for cancer, including self examination or going to the doctor, you may be inviting the cancer into the body. Some women also shared that self-examinations were identified by some Aboriginal community members as "touching yourself" and as something which should not be spoken about. Marjorie said: "when I said I did breast self-exams, my cousin [said] 'Oh, you play with yourself?'"

Some of the women's own silence surrounding breast cancer is related to the loss of body parts, hair loss and experience of being ill. When diagnosed at a young age, Marion found it difficult to talk about being ill. With time came the ability to talk about her experiences. She said, "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 also talked about the onset of early menopause because of breast cancer treatment and being "ashamed" about this experience.

Hair loss was "one of the hardest parts of cancer" for two of the participants.
Marion was unwilling to go through chemotherapy for fear of losing her hair. She shared "[I] cried and cried" when her baby pulled off her wig in front of her husband. Sandra talked about wearing hats, but in contrast to Marion's account, Sandra said she wore them more for other people's comfort. She describes the following photograph: "It reminds me of being bald. It reminds me of hiding. Those are the hats I had to wear. It is hiding stuff" (see Photo A).

Sandra also took a photo of masks, saying, "There were days when I felt like I could be this or I could be that. I could be all crazy, messed up, but you know, there were just masks that I used to make other people feel comfortable" (see Photo B).

A third photo captures this idea of being exposed through a diagnosis of cancer, along with the desire to hide as expressed by the masks and the hats. This photo shows Sandra standing in a tipi outside a First Nations University. She explained the photo in the following way:

This one here is a tipi where I'm standing inside of it. It's a skeleton. The skins are missing, so I'm exposed is what I'm saying. You see the past and the present, with the new university...you can very much see that I'm an Indian. (see Photo C)

Thus, our initial theme captures various ideas about shame, silence and being at once hidden and exposed as the participants experienced intersections of Aboriginality, racism, age and gender.

The second theme of resilience and strength relates to participants' identities as young, Aboriginal women and varying degrees of racialized histories. Some women spoke about the experience of residential schools, either their own experiences or those of their parents or grandparents. Some women spoke about violence in past relationships, or losing family members to cancer. Many women believed that these experiences provided them with strength and resilience to survive breast cancer.

Tina and Marjorie shared stories about their own resilience and strength as connected to their childhood experiences in foster care and in residential schools. Marjorie said that these experiences made her strong enough to deal with cancer.

I just refuse 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...I have my part to do and I have my things to teach people.

In reference to surviving residential school, Marjorie said: "...what [the residential school] tried to beat down in me, brought something up that's been hidden and I'm a better person for it."

All of the women expressed that their experience with cancer contributed to their current strength and had a powerful influence on their current attitudes, experiences and approaches to life. Marion said:

How you go through [breast cancer] 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.

Similarly, Sandra showed how her experience of transformation was connected to her roles as a young woman with breast cancer:

You know I, I saw these, uh, beautiful flowers...so I saw these
beautiful flowers and they were all covered with these little white butterflies, so I stopped to look at them and I thought, that's so pretty and all of a sudden all the little butterflies came flying up around me and I was like, "gasp"...But I mean I, I cry over everything now, like good tears of joy...I'm happy to be alive and, I'm thankful...you know, I think I've become a better mom, a better wife, a better person.

The resilience and strength of the women in this study extended to their willingness to support other Aboriginal women with breast cancer, particularly young women. All of the participants talked about what types of support they needed which is our third theme. Participants suggested that support was related to the inter-connections among emotional and informational support, economic survival, racial barriers and environmental concerns. All of the participants described various types of support they wished they had received. Captivatingly, woven into the fabric of the participants' descriptions of the need for support were also reflections of their strength and resilience. Every one of the participants spoke about their desire to support other Aboriginal women as a partial solution to the type of support they had been missing in their experiences as young and marginalized Aboriginal women.

Many participants shared concerns about their economic needs directly related to breast cancer, including prosthetics, brassieres and medications. They also shared concerns about the social and environmental conditions, such as surviving economically, housing conditions on reserves, residential schools and violence. Housing conditions and a prevailing "silence" surrounding cancer (especially breast cancer, as shown previously) forced two of the women to move away from more remote areas in Saskatchewan and away from their families to improve their cancer care. Cheryl shared that she spent more time worrying about how she was going to be able to support herself while she was sick, than the cancer: "...I was under a lot of stress because of my financial situation - being single, and my EI was running out."

Donations from her community allowed her to survive, as she expresses visually in the following picture (see Photo D).

Sandra also discussed these same economic themes, connecting them to the importance of culturally and economically knowledgeable care that would meet the needs of financially underprivileged women:

They [support group] were talking about going on holidays, taking time off work and taking their family to Hawaii when they were diagnosed and I was like...I can only dream of that. But, I can't even afford the bra. Like I need a bra and I can't afford it. And at the end of it, [a woman said], "Well, I'll buy you a bra." And I said, "Well, thank you, but you're not really getting my message here...You're gonna buy us all bras?!"

Sandra also talked about pressures on young Aboriginal women who are parenting: "A lot of Aboriginal women raise the children by themselves...You can't afford to be sick. You can't let yourself be sick." Sandra captured this issue in the context of her employment:

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."

(See Photo E)

Marjorie's experiences of support and ideas for supporting young, Aboriginal women echo Sandra's experiences and concerns:

Two volunteers came to me a couple of times and they didn't do
me any good. They couldn't grasp the concept of me being a First Nations woman. They were Caucasian. They couldn't differentiate that I had my own unique pattern and problems, but the damndest thing is, at the time, the next youngest person on chemo was 62. So, they couldn't relate and I couldn't relate to them because I had a little baby. They were grandmas.

Marion suggested that she felt a great deal of guilt associated with child care during her illness in that her children were so young and had to grow up so fast:

My daughter was only then fifteen...I had four kids...my daughter, she practically looked after everything while I was on chemo and going through cancer: You know like, and sometimes like I, I blame myself that she never, she never had her freedom like that. For years she stayed home and took my place. Like cooking, cleaning when I was gone for chemo, she'd be watching the kids.

At the same time, many women survived to support their children. Marjorie talked about the fact she survived breast cancer at such a young age because she had a small child. She is now a young grandmother, and the photo of her with her grandchildren was particularly meaningful to her, thereby illustrating some of the connections between children, age and support (see Photo F).

Tina stated that becoming healthy would be easier with age appropriate and culturally sensitive support:

The [support center] were older people. Not that I had a problem with anybody that was older than me, I just needed to see somebody that was my age...And every single person, there were ten of us in there, they were all grey haired. I was the only one I think that was dark haired and I felt, so out of place...They need to group people.

These comments were echoed by another participant who said she went to a support group, but it was comprised of "old, white ladies." This woman then used humor to describe the lack of resources for young, Aboriginal women and the need for them. She mentioned the popular Chicken Soup series of books and said, "It would be great to have something like that - Soup and Bannock. It would be funny, but important. I think that the stories are out there and [need to be] in a form people can access." Marion said:

I would love to see a support group like, like, like the cancer society with Native people, to help Native people. I mean it would really help. Like, like helping from experience. I wish I would have had a Native person to talk to, and help me through everything I went through. Like even today, I wished...like I would still love to talk to a Native woman and help me, because I still live with fear....I'm willing like to share because [sharing] ...that's how you get your story out, that's how you let other people know that there is support out there for you...that you're not alone.

Thus, participants identified the need for both age and culturally appropriate forms of support and showed a keen interest in transforming current practices themselves.

Discussion

It is difficult, if not impossible, to disentangle the influences of social factors such as gender, ethnicity and age. Some of our findings may resonate with both Aboriginal and non-Aboriginal women's
experiences, but other concerns may be more specific to Aboriginal women or women with low incomes. Likewise, in some discussions, age is paramount, while Aboriginality is talked about less. What the interviews and photos do highlight, however, is the need for health care practices and policies to recognize the intricacies of identity and the complexity of lived experience. At the same time, health care practitioners, breast cancer organizations and support groups have not provided space or context in which the complexity of identity can be reflected upon or discussed. For instance, there is a dearth of visible minority women in most print and visual breast cancer resources, and few, if any resources, are geared toward those women who are both young and members of ethnic minorities.\(^2\) Faced with silence and stigma surrounding breast cancer, young Aboriginal women may not be in a position to ask for support or may feel ashamed about their experiences, even with close family members.

The ideas expressed surrounding the theme of support serve to illustrate Aboriginal conceptions of health and healing which exist within the context of family (Ellerby \textit{et al.} 2000). Attending support groups populated by older, white women was not as helpful for our participants. Their suggestions for age appropriate and Aboriginal support groups point to the necessity of incorporating Aboriginal conceptualizations of health and holism into health care practices. Likewise, participants show that gaps in experientially-based breast cancer research (i.e., a lack of diversity) are significant and should be addressed. Some of our participants show that their experiences as Aboriginal women are unique.

While we would not rule out the possibility that non-Aboriginal women with breast cancer might simultaneously feel exposed and invisible, this juxtaposition appears to revolve around a feeling of vulnerability linked to being easily identified as Aboriginal. In some cases, it has a direct relationship to experiences of racism. Perhaps these experiences provide solid evidence of marginalization and the effects of colonization. The women may be simultaneously identified, but hidden in that their ideas, experiences and values are not heard or valued.

The feeling of being exposed and vulnerable also has a sophisticated connection to shame and silence about various aspects of breast cancer treatment (such as hair loss and surgery). At the same time, the experience of not being seen, of being invisible, seems to revolve around others' lack of understanding about the complexity of these women's lives in terms of their various roles as mothers, as Aboriginal women, as people living in poverty (in some cases), as practitioners of traditional Aboriginal medicine (in some cases). Moreover, the idea of not being visible also relates to the need for more support and understanding from health care systems and survivors' groups. Broadly, participants' words and photos affirm the idea cited earlier that Aboriginal health is reflective of a "complex web of physiological, psychological, spiritual, historical, sociological, cultural, economic and environmental factors" (Waldram \textit{et al.} 1995, 3).

**Conclusion**

A key component of completing research with Aboriginal peoples is that the participants benefit from their involvement individually and politically. Our findings suggest that photovoice methodology is an empowering method suitable to completing research with young Aboriginal women. The women represented their communities through the documentation of their life experience through photography. As a result of their work, the women have also been offered an opportunity to assist in the development of relevant policies and have met with representatives of the Breast Health Centre in Saskatoon. The participants have also contributed to work being done by the Saskatchewan Breast
Cancer Network and Breast Cancer Action Saskatchewan.

Photo A

Photo B

Photo C

Photo E
We use the term "Aboriginal" to refer to diverse cultural groups in Saskatchewan, including those who are First Nations and Métis, while recognizing that "Aboriginality is a social construct with little grounding in the day-to-day realities of the heterogeneous groups to which it refers. Tremendous cultural, historical, socioeconomic and political diversity exists between and within these groups" (Smylie 2005). We did not impose specific definitions upon potential participants. Rather, women who were interested in participating in our study self-identified.

2. The Canadian Cancer Society’s website contains no publications geared specifically toward Aboriginal women. Further, while the Canadian Breast Cancer Research Alliance has a list of many searchable terms in its research database, ours is the only project that is returned in search results for Aboriginal women, and, while the American Cancer Society has produced a publication for minority women, its emphasis is upon prevention and risk factors, not survivorship.

Acknowledgements
The authors wish to acknowledge the generosity of our participants. We also thank Alana Ferguson, Maureen McIsaac and Laurie Schimpf for research assistance. Our work was supported by the Canadian Breast Cancer Research Alliance and the Social Research Unit in the Department of Sociology, University of Saskatchewan.

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**Photo Credits**

Photo A

Photo B

Photo C
Person in Photo: Sandra Ahenakew
Photo Credit: Sandra Ahenakew, 2006.

Photo D

Photo E
Person in Photo: Sandra Ahenakew
Photo Credit: Sandra Ahenakew, 2006.

Photo F
People in Photo: Left to Right Dallon Quewezance, Kayla Quewezance, Marjorie Quewezance, Kelly Sinclair Quewezance
Photo Credit: Marjorie Quewezance, 2006.