

**FAMILY, LOSS, AND PLACE: EVERYDAY EXPERIENCES OF HEREDITARY  
CANCER IN A FIRST NATION COMMUNITY**

by

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## **ABSTRACT**

This thesis examines how people from a First Nation community, where a unique hereditary BRCA2 mutation has been identified, perceive their risks for genetic disease. The study is based on participant observation and interviews with people from the reserve (mainly women) who have received genetic counseling and testing, as well as those who have not. Additionally, people on the reserve are worried about the affect of environmental toxins on cancer in their community, a concern that predates the identification of the BRCA2 mutation. Using a grounded theory approach, this thesis argues that cancer in this community is experienced in relation to changing roles in the family, the loss of family members due to cancer and other causes, and sense of place and its affect on views of cancer. The result is a sense that the community as a whole may be just as “at risk” as the individuals and families that have the identified mutation.

## **PREFACE**

The author conducted all of the research presented in this thesis. The BC Cancer Agency - Research Ethics Board approval number is H08-01474.

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*For Elisa*

## INTRODUCTION

Research on the social implications of genetic testing have led most geneticists to view genetic diseases as conditions that affect whole families rather than simply individuals. Knowledge of genetic diseases in families can influence family relationships, whether close or extended, and reciprocally notions of kinship and family relatedness often affect individual and family understandings of genetic disease (Wexler 1995; Richards and Ponder 1996; Richards 1997). Less clear is how people who live in small or remote communities—where most people may consider themselves related to one another—understand genetic disease. I explored this question on a First Nation reserve in British Columbia where clinical geneticists and counsellors have identified a unique breast cancer mutation in the gene BRCA2 among a number of individuals living in the community. I found that even though knowledge of hereditary risk affects extended family members as expected, people experience that risk as part of the legacy of colonialism they continue to face in their everyday lives. There are three related aspects of this experience: the family—in terms of the interdependency among relatives, intergenerational relations, and gender roles; the loss of loved ones due to cancer and other causes; and the significance of a sense of place on community relationships and people's understanding of cancer.

Since many people prioritize aspects of colonial history over genetics and family health history, it is important to distinguish views of cancer from hereditary risk. Hereditary risk is normally determined first through the documentation of a family pedigree focused on genetic relatedness and the family's medical history, and then, if appropriate and desired, predictive or susceptibility genetic testing is offered. The way

people understand family relatedness in everyday social terms influences the way people perceive hereditary risk (i.e. family genetics) in complex ways. By teasing apart this relationship, I reveal the way that cancer may symbolically represent the continued experience of colonialism for people in this community. I begin with a brief background of the study, and overviews of hereditary cancer genetics, genetic testing, and the role of genetic and social relatedness in views of hereditary risk. Next, I present the research method, themes from the interviews, my discussion of these themes and concluding remarks. In addition to the nature of cancer and the experience of hereditary risk, this thesis deals with issues of kinship and community relations on a First Nation reserve. I show how knowledge of hereditary risk may highlight social tensions in the community in addition to conveying the probability of illness. Reciprocally, social relationships and relations between people and places (past and present) may affect the way people interpret hereditary and other risks. The result is a sense that the social and cultural fabric of the community may be just as “at risk” as the lives of individual mutation carriers and their extended family members.



## **BACKGROUND**

The particular BRCA2 mutation that is unique to this community was first identified by the clinical genetics staff at the Hereditary Cancer Program (HCP) at the BC Cancer Agency (BCCA) in Vancouver, British Columbia. This unit specializes in identifying hereditary risk and offering and interpreting genetic testing for a number of hereditary cancers including breast/ovarian, colon, and other less common cancers. The HCP had screened breast cancer patients from an Interior Salish<sup>1</sup> reserve in BC, as well as some relatives of the patients identified as having a mutation. Based on their examination of family pedigrees and DNA analysis, HCP staff suspected that additional individuals in the community might also be at increased genetic risk, though the level of risk was difficult to determine without further investigation. The clinical genetics team provided a community information session on the reserve to explain the nature of hereditary risk, and offered opportunities for further analyses of family health histories and genetic testing. Through consultations with the patients and relatives, it became clear that, in addition to questions about hereditary risk, people in the community also had concerns about environmental exposures and risks for cancer. My graduate research began at the invitation of the HCP, as part of the response to these clinical and community concerns.

From the start of my fieldwork, the seemingly contradictory way that people spoke to me about cancer risk in the community puzzled me. Those who have or are at risk of having a mutation in BRCA2—and who are at increased risk of developing cancer—seemed to prioritize hereditary risk as the primary risk for cancer facing themselves and their families. However, like those with no known risk for the hereditary mutation, they also identified a variety of risk factors in addition to family history. These

include fears of learning that one has a mutation, fears about the nature of cancer and how it develops, and concerns about other health and social issues (e.g. arthritis, alcohol use) affecting the community. Moreover, people in the community and in the region are concerned about the relationship between cancer and environmental toxins from the local railway and hydroelectric power lines. For this reason, people in the community may give less emphasis to clinically identified risks (e.g. the risk of transmitting the gene mutation to offspring).

## **HEREDITARY CANCER AND RELATEDNESS**

### **Genetics, Breast Cancer, and the Environment**

In recent decades, increased knowledge about the molecular basis of breast cancer has led to the identification of genes and alleles associated with the risk of development of this illness. Foulkes (2008) identifies three main classes of “susceptibility genes”: “high penetrance” or “tumor suppressor” genes, “moderate risk alleles”, and low risk alleles. The gene mutation identified in this community is the tumor suppressor gene BRCA2. The pattern of inheritance of BRCA2 mutation is autosomal dominant, meaning that familial inheritance from just one parent is sufficient to translate into increased risk for the disease. However, having either of these mutations does not guarantee that an individual will develop breast, ovarian, or other related cancers. Less than 10% of cancers in the general population appear to result from mutations that are inherited in single genes (Foulkes 2008: 2145), and 5-10 % of breast cancers overall are hereditary. However, for those who have BRCA1 or BRCA 2 mutations the lifetime risk of developing breast cancer is within the range of 47-66% (Chen and Parmigiani 2007).

Even where individuals have a mutated gene, cancer genetics research has demonstrated that *non-genetic* factors also have an influence on breast cancer risk and disease expression (King et. al. 2003; Simchoni et. al 2006). Geneticists refer to this as the “two-hit” model, the hypothesis originally proposed by geneticist and physician Alfred G. Hudson in 1971. Foulkes explains the two-hit model of cancer genetics as follows:

In hereditary cancer syndromes, one abnormal copy of the gene is inherited in the germ line from either parent, whereas the other copy is inactivated in a somatic cell, typically because of random processes whereby genes, chromosomes, or both are rearranged, deleted, or replaced. [Foulkes 2008: 2143]

In other words, individuals with inherited mutations may be at an elevated risk for developing breast cancer because they begin with one defective allele that is present in all cells in their bodies. Environmental factors (e.g. chemicals, radiation) may damage the remaining allele, which in turn can disable the cells' ability to suppress the development of the somatic mutations that result in cancer. This hypothesis may explain a variety of cancer etiologies, though its relevance for this present study relates to the possible influence of environmental factors on cancer risks for BRCA2 mutation carriers. In addition, clinical geneticists have not identified the particular BRCA2 mutation found in this community in other populations so there is no relevant information on the penetrance of this mutation or on its expression. Consequently, its unknown origin raises questions about the possibility of a unique, novel germline mutation in the community's history. A summary of this history is necessary to understand the complexity of hereditary risk perception in this community.

The main question participants raised in our interviews was *where did cancer come from?* The hereditary aspect of this disease aside, most agreed that local hydroelectric towers are exposing the community to electromagnetic radiation and that PCBs in the oil from transformers used on reserve roads also posed a hazard. Importantly, participants framed their fears about toxin exposure within discussions of everyday activities and their locations (e.g. of housing, work, or fishing and fruit-picking sites). The significance of these fears and concerns about the environment and cancer are not simply a matter of time, but are couched in perceptions of environmental risk and explanations of cancer causation within discourses about the community's colonial history. Cox and McKellin (1999) have shown how people from Huntington's Disease

families experience hereditary risk within the social context of everyday life, an important issue that I will return to below. Here I would simply like to note that concerns about the environment on the reserve pre-date the identification of hereditary risk in the community, a fact that partially explains the emphasis on environmental risk.

A significant period in the history of this community is the Gold Rush of the late 1850s. Geographer, Cole Harris writes:

The coming of outsiders to British Columbia was late and abrupt: along the middle Fraser a few fur trade decades, then a gold rush. Miners brought one overriding objective, the attainment of which rendered Native peoples and nature expendable. No miner fretted about the ecological effects of the millions of tons of overburden sluiced into the Fraser River. There was no other means of disposal: the river was accommodating, and that was that. [Harris 2009:7]

In addition to the salmon shortages and land encroachment that resulted from the population boom, the need to transport equipment and supplies to the Interior gave impetus for improved transportation through the region. Construction of the Pacific Great Eastern Railway—later called BC Rail, and then bought by Canadian National Railway—began in 1912. The establishment of this railway and the people that came with it resulted in more encroachment into First Nation communities' territories, as well as damage to local fishing and hunting grounds and agricultural lands. It also facilitated further development. Between 1946 and 1960, hydro projects once again brought an influx of people to the local region, including the reserve.

One elder I spoke with recalled this period as one of temporary prosperity for the community. Most people, whether they lived through it or not, described the construction of the hydroelectric towers as a time of change and struggle for control of lands and resources. Like in other aboriginal communities across Canada, residential schooling was also in effect during this period, posing a threat to the transmission of local language and

culture. In her poignant analysis of the death of an aboriginal child from Alert Bay, Culhane Speck observes that, “For most urban Canadians, history is, perhaps, a personal interest, a curiosity. In rural/White communities [...] history is an ever-present reality” (1987:67). For the people I spoke with, the railway and hydro plant, and damage to the environment that people attribute to both, stand as constant everyday reminders of the community’s colonial history. However, proving environmental causation for sporadic mutations is challenging because in order to rule out other causes of the mutation, the people and place in question would need to be relatively isolated from environmental influences of other people and communities.

To the frustration of a few people I spoke with, much of the research regarding the relationship between the environment and breast cancer risk is either poorly understood or inconclusive (Coyle 2004). The Band has pursued several avenues of research on environmental toxins, as far as funding would permit. Findings from these studies have been difficult to locate, and one man who declined participation in the study told me that his community had been over-researched but no results had come of it. Some people also expressed frustration that these studies produced few changes to the way these industries operate. Not surprisingly, they view this as a neglect of their concerns and a perpetuation of the historic injustices inflicted upon aboriginal peoples in BC. For these reasons, it is impossible to appreciate the impact of hereditary cancer on the community without accounting for its colonial history and the related worry about environmental risks.

## Genetic Testing and Breast Cancer Risks

In British Columbia, testing for hereditary mutations in BRCA1 and BRCA2 is available to individuals and families who meet generally accepted Canadian testing criteria. The aim of these tests is to either identify a mutation in a family (“index” testing), or see if a known mutation is present (“carrier” testing). The BCCA Hereditary Cancer Program website explains that while these genetic tests are relatively straightforward, interpreting the results is often complex.<sup>2</sup> This is in part because of the sheer number of identified mutations (several hundred) in BRCA1/2, and because most families tend to have unique mutations. Consequently, index testing must result in a mutation identified in a person with cancer before carrier testing is possible for relatives of patients. Third party family members (siblings, cousins, and their descendants) may or may not have interest in the genetic test results of a family member, which further complicates the process of testing, as well as the roles and responsibilities of clinicians, medical geneticists, and genetic counsellors (Hallowell 1999; Doukas and Berg 2001). Counseling families can be problematic *beyond* the clinical context, however, because of the complexity of family dynamics and because hereditary risk is experienced in relation to family and other everyday life concerns (McKellin 2001).

Differences in the models used to understand and assess genetic risk are particularly problematic when people assume relationships based on social and cultural norms, but the particular genealogical ties remain unknown. When they do correspond, it is often because the (English) kinship system resembles a Mendelian genetics model of inheritance (Davison 1997; Martin 1997), but those assimilating genetic information will not necessarily understand it in terms of the scientific model that produced it. As Cox and

McKellin argue, “[r]esearchers must go beyond clinical settings in order to focus on how at risk individuals understand hereditary risk in everyday life” (1999:623). As I will show, people in this community may minimize the clinically defined risks for hereditary cancer because other interrelated concerns about the environment and loss of loved ones take precedence.

In addition, people in the community do not understand kinship based solely on those ties that geneticists and counsellors can trace in a pedigree. As in many aboriginal communities, kinship on the reserve is broad and inclusive and the distinction between friends and relatives is not always clear. Notably, none of the studies mentioned above consider how cultural notions of relatedness and inheritance through families may play a role in shaping lay models of risk in small communities with historically dense inter-relationships among families. In these kinds of community contexts, people who are “kin” are not necessarily biological relatives, although they may assume biological ties exist. The complexity of clinical and community genetics and their social interpretation in a small, geographically remote community is captured by one woman’s remark to me during my fieldwork. When I asked what her relationship was to some of the breast cancer patients, she just laughed and exclaimed, “We’re all related here!”

## **Relatedness, Community, and First Nation Health**

### Relatedness, Family, and Community

From an anthropological point of view, we must account for people’s constructions of family relatedness outside of a clinical genetics context to understand their views of risk. Years of debate and cross-cultural comparison within the discipline have proven that it is inadequate to assume that biology is the true basis of kinship. Schneider (2004 [1972])



was the first to challenge the assumed biological basis of kinship, arguing that kinship was itself a western social construction that assumed an inherent separation between “social” and “biological” relations (Carsten 1995:225). For many anthropologists kinship became a system of cultural symbols rather than relationships of descent, membership, and affiliation. Furthermore, Carsten demonstrates that social and biological relations may be separated (or associated) in ways that are culturally specific, re-defining kinship as “the relatedness that people act and feel” (Carsten 1995:236). In other words, if everyone in a community believes that they are “related” to one another, how do they demonstrate and experience their relatedness? Stated otherwise, what is the basis of this relation if not biology?

A re-occurring refrain that I heard from the people in this historically Salish speaking community was that they considered themselves “related” to everyone on the reserve. Nonetheless, the biological details of these relations were sometimes vague or unknown. For example, Naomi, an elder in the community who has had cancer and tested positive for the mutation, laughingly explained to me: *“I don’t know anybody ELSE that has cancer other than the relatives, ‘cause most of the people around here are all our relatives!”* This was evident by the terms “auntie”, “uncle” or “cousin” that the people commonly used in everyday social encounters. However, as authors of a handbook on tribal mental health caution:

[...] newcomers tend to assume that someone addressed as “auntie” is in fact the speakers’ biological aunt. However, this may or may not be the case. Even more commonly, new-comers may fail to take proper note of the complex family ties existing between tribal members. [*Swinomish Tribal Mental Health Project 1991: 147*]

Historically, Salish kin terms reflected the complexity of kinship (see Elmendorf 1961) and the social aspect of family relationships. Today, these nuances are harder to locate in

the language. For example, among Flathead Indians, people often use simple English kin terms such as *auntie* or *uncle* (along with simple Salish terms) instead of traditional kin terms that may specify lineage, gender, or generation (O’Neill 1996: 224-225). The Canadian-English meaning of these terms should not be taken for granted however, as their use signifies “respect” and “expresses the emotional and psychological relationship existing between individuals of different generations” in some traditional indigenous societies in North America (*Swinomish Tribal Mental Health Project* 1991: 146).

Anthropological studies of First Nations in this region paint a distinct picture of kinship from several sub-disciplinary perspectives, including linguistics and archeology (Teit 1900; Anastasio 1955; Elmendorf 1971; Hayden 1992). The principal key features they emphasize are the complexity and flexibility of social groups. Based on archaeological evidence, Hayden (1992) argues that a high incidence of sharing and generalized reciprocity, mobility between resource locations, and flexible alliances with neighboring groups, among other things, characterized this complexity. Anastasio similarly contended that “[i]n the Plateau the most important dyadic relations were those between adjacent groups. These dyads were strongly linked by intermarriage, co-utilization of resource and settlement sites, cooperation in various tasks, alliances for war, and intergroup ceremonies” (1955:42).

Sharing and generalized reciprocity and the flexibility or “indeterminacy” of family groupings are also key features of family systems in Miller’s (1989) examination of the election of Upper Skagit women to political office. Despite his focus on Coast Salish people of Western Washington as a case example, Miller (1989) provides a useful framework for understanding the historic complexity of family networks documented by

anthropologists among First Nations generally. Describing “family” as the central organizing economic unit, he contends that the value of collectivism forms the basis of the “family ideology” (1989:107). These families are distinct because they “organize many of the fundamental features of the lives of their members, which is to say that they have corporate functions, including, in many cases, those affecting fishing, ritual life, [and] regular small scale reciprocity” (Miller 2007:19). An important aspect of this corporate family dynamic is they rely on intergenerational relationships to care for children and elders (Miller 1989:108).

Furthermore, corporate families are “temporary coalitions” (Miller 1989:111) with flexible membership, a factor tied to the political and competitive aspect of families. Miller’s description of member recruitment is worth reiterating, as it shows how genetics does *not* determine family:

Recruitment to the family occurs through birth to family members, except to peripheral members such as children from an earlier marriage or an inmarrying spouse; by marriage [to a] family member; and through change of residence and affiliation with a family who acknowledges this affiliation, in effect activating a latent tie after moving on the reservation. [Miller 1989:109]

The flexibility of family membership that Miller and others have noted is evident in the genealogies I collected during my fieldwork. Changes in household membership are common, as are multiple marriages (common-law or otherwise), half-siblings, adoption and foster care, though some people were hesitant to discuss the details of some of these family dynamics. I suspect that this apprehension was really concern about how outsiders might interpret these non-nuclear family structures. As I discuss below, they may also worry about the affect of strained social relations, and talking about them, on their health and well-being.

Additionally, more than a century of missionaries, residential schools, disputes over land and resources, and Indian Act definitions of who is and is not “Indian” have undoubtedly shaped how aboriginal people in BC construct relationships and identities. The lasting effects of residential schooling may further complicate relationships among today’s aboriginal families and communities. The separation of children from families and communities contributed to the loss or disruption of culture and language, as well as the social relationships necessary for learning. Nonetheless, anthropological studies indicate that the complexity and flexibility of First Nation family organization in B.C. have endured despite colonial interference (Hawthorn et. al. 1965 and Lewis 1970). My purpose here is to point out the complexity of social networks that characterize First Nation families, not to detail this history. The point is that the interconnectedness of community relationships will have an influence on the way individuals understand family relatedness and genetics.

This interconnectedness will also have clinical (genetic) implications. Historically, marriages between first cousins were taboo. At the turn of the 20<sup>th</sup> century, Charles Hill-Tout noticed a shift in generational views regarding marriage, commenting that: “The old people expressed astonishment that first cousins, who with them are regarded as ‘brothers’ and ‘sisters’, should be permitted by us to intermarry” (1905: 107). As Teit explains, exogamous marriage was socially sanctioned:

The Lower Thompson [*Nlaka'pamux*] favoured marriages between members of different villages. Cousins were forbidden to marry, because they were of one blood, similar to sister and brother; and the union of distant relations was discountenanced. Even if second-cousins married, they were laughed at and talked about. If a man resides with his wife’s people for a year, and makes his home mostly among them, he is considered a member of that tribe or band. The same is the case with a woman who lives among her husband’s people. [Teit 1900, 325]

Though Teit only hints at the way people might have experienced family relations, his description exemplifies how kinship is often a social, rather than biological, phenomenon. Moreover, his description points to the potentially complicated social and genetic relations that might result from a historical practice of exogamous marriage between a set of villages.

### Relatedness and Health

Aboriginal people have distinct (and varied) worldviews that include concepts of health, illness, and healing that may differ from medical genetic and clinical perspectives.

Central to these concepts are the notions of family and relatedness discussed above. A very brief review of these concepts and their relation to family relatedness is important because they help us to understand the variety of fears people expressed to me, and how people view risks for cancer in relation to their families, their community, and their environment—today as well as in the past. Aboriginal concepts of health also provide insight into the kinds of strategies people in the community might use, or want to use, to cope with cancer.

*A Gathering of Wisdoms (Swinomish Tribal Mental Health Project 1991)* is a handbook on the cultural dimensions of mental health in American Indian communities that contains a contemporary overview of traditional concepts of health and illness. Despite the mental health focus and the context of Coast Salish peoples south of the border, the handbook is useful for understanding some of the seemingly contradictory views of the First Nation (Salish) people in this study. I would like to emphasize three main points from this handbook. First, the worldviews of aboriginal people are holistic, assuming connections between people and their environment; second, people often think

that ill health results from an externally caused imbalance; and third, the same symptoms may have a variety of causes that may only be determined with careful attention to the specific context (*Swinomish Tribal Mental Health Project* 1991: 138-139). In addition, medical or scientific explanations of illness are not primary but rather, people consider them alongside other physical, social, or spiritual causes (*Swinomish Tribal Mental Health Project* 1991:138). For this reason, “fear” may be a much too simple characterization of perceptions of cancer and decisions around testing, though it is indeed how people described their own concerns.

Notions of relatedness are intertwined with concepts of health and illness because holistic worldviews regarding the self and spirituality entail that good health is not merely a physical state of being. As the tribal mental health guidebook advises:

*The idea of being in balance or of being right in the world, and especially to one’s family, kin and significant others, is of central importance in most Indian cultures. This includes being in balance with the natural and spiritual worlds. To be “well” means keeping the right balance in all things. Similarly, illness is due to some imbalance and is in itself an imbalance. In the Indian worldview, illness may be caused by a mistake or a misdeed on the part of the ill person, their family, or some other person. [...] Because of the close connections between individuals and family members, the actions of one’s family are often seen as having positive or negative repercussions for the individual. [Swinomish Tribal Mental Health Project 1991: 138, italics in original]*

Despite the reluctance of some people to discuss spousal relationships or strained relationships they had with some of the members of their families, the importance of “family” for health was evident. However, my questions seemed unable to penetrate the depth of its significance to reveal the unspoken terms by which people feel related.

By carefully analyzing the interviews, I realized that the participants and I understood kinship in fundamentally different ways. Determined to find out what it is exactly that make them feel related to others in their community, I could not initially see

that their primary concerns are the things that *threaten* social relations both today as well as in the past. O’Neill (1996) similarly remarks that:

To many Flathead people [...] it is the instances in which relations of reciprocity have broken down that occupy the imagination. Thus family and friends are not only the principal source of comfort and joy but also the principal source of pain and discomfort. [O’Neill 1996:109].

By causing illness, and in worst case scenarios, the death of family and community members necessary for reciprocal relations, cancer ultimately threatens to “break down” everyday social networks at the heart of community life. It is the experience of this threatened or “at risk” notion of kinship and community that I attempt to elucidate here.

## **METHOD**

I first visited the reserve briefly in October 2007 following a band council member's request that the HCP help the Band to understand the cancer risk in their community. Following this visit, the Band formally approved a request to conduct this community-initiated research. During August 2008, I stayed with an elder couple in the community while I conducted my fieldwork. The purpose of my fieldwork was to investigate the social and cultural context that shapes views about hereditary cancer on the reserve. I spent four weeks on the reserve collecting interviews as well as family medical histories, with hope that this might further illuminate the nature of the relationships within the community.

### **Description of Study Cohort**

In total, I interviewed 15 members of the Band and conducted brief (20-30 minute) follow-up phone interviews with seven of these same participants. Out of this cohort, 13 participants were women and two were men. The birth year of participants ranged from 1930 (oldest participant) to 1982 (youngest participant). In this range, four were born in the decade 1950-1959, four in 1960-1969, three in 1970-1979; the remaining three participants were born before 1950 (two) and after 1980 (one). Additionally, eight participants had been through genetic counseling and testing at BCCA, while the remaining seven had not. As part of their consent, these same eight participants (all women) granted permission for me to access their BCCA medical records for the following information: a) a summary of their medical history; b) details regarding their family history; and c) genetic test results. Out of these eight women, seven had tested positive for a familial mutation and one had tested negative. Out of the seven individuals



who had *not* been through testing or counseling, five had at least one first-degree relative (sibling or parent) who had tested positive for a familial mutation and thus were at increased risk. The remaining two considered themselves related to people in the community but did not appear to have first-degree relatives who had died of breast cancer or who had a positive mutation status. Finally, only five participants in the study have had and received treatment for hereditary cancer related to BRCA2.

As in most studies of BRCA 1 and 2 testing, men are significantly under-represented in this study and the family histories of breast cancer patients are maternal (see Richards 1999). These numbers may reflect recruitment methods as well as the fact that there are currently no known cases of BRCA2 related cancers among men on the reserve. With permission from the Band, the first step of recruitment entailed inviting those who HCP staff had counseled or tested to participate in the study. On behalf of the study and with ethics approval from the BC Cancer Agency, clinical staff at the HCP sent letters of invitation to 16 people who had been part of the clinical uptake from this community. In addition, my hosts alerted others of my presence in the community during the initial period of fieldwork, leading some individuals to approach me directly. At the end of each interview, I also asked participants to pass on information to interested family members.

### **Data Collection and Analysis**

The primary qualitative research methods for this study were participant observation in community activities, and semi-structured, face-to-face interviews with individuals from families at risk for BRCA2 mutations.<sup>3</sup> As part of the interviews, I also recorded family genealogies. In addition to the general biographical information, the interview questions

focused on issues of health and genetics. Specifically I asked about the individual's health and family history; their knowledge and experience with cancer; their understanding of the health risks faced by their family and community; and community social relationships generally. These interviews lasted on average from 60-90 minutes and took place in relatively familiar settings, such as the participant's home or at the community health centre. With the participants' permission, I recorded and later transcribed all of the interviews either in full or part for the purpose of analysis. To identify the participants' explanatory models I analyzed the interviews using the sociological grounded theory method (Charmaz 2006). This method helped me to identify themes in the interview data as they emerged organically in the text.

### **Fieldwork**

My fieldwork took place in August when many in the community spent their days, if not nights, at the local fish camps. Timing my visit during fishing season helped me learn about relationships between families who shared certain fishing grounds, although it also made the recruitment of males into the study more challenging. To become acquainted with people on the reserve, I accompanied my hosts on their daily outings, and they facilitated meetings with individuals interested in research about health, medical care and perceptions of cancer risk. In addition to visiting fish camps, I explored some cemeteries, the nearest museum, and even the local dump during some of our excursions on the reserve and in the region. These outings provided me with opportunities to observe and ask questions about social relationships in the community, and gave me a sense of how people live rather than talk about the relationships that frame their perceptions of hereditary risk.

In some interviews concerned primarily with health and social problems facing the community, participants conveyed a sense of strained relations that counterbalanced the community connectedness I witnessed publicly. When talking about life on the reserve, several people lamented the changes to their community over their lifetimes and those of their ancestors, or focused on the tragedies they and others have experienced. It is important to keep in mind that this portrayal of the community is not representative of all aspects of life on the reserve, nor of all their experiences of cancer. Many participants also spoke of the positive strategies they use to cope, such as diet and lifestyle changes that involve the revitalization of cultural practices to do with subsistence. Some were returning to the land to gather and cultivate foods that they could preserve for the winter, such as berries, apricots, and vegetables. Having provisioning for the cold winter months is particularly important because there is no supermarket on the reserve and bad road conditions can make traveling by car or train difficult at best. None of the participants I spoke with complained about the barriers to accessing fresh fruits and vegetables, but many felt that an improved diet was important for health and cancer prevention, and that re-vitalizing traditional subsistence practices would be the best means of achieving this.

### **Genetics, Health, and Aboriginal Research**

Social science research about genetics, health, and aboriginal communities presents several challenges that I grappled with throughout the course of this research. One challenge was to define the boundaries of “community” in the context of a First Nation reserve where people come and go, occupants of houses change, and people who are considered part of the community or members of the band may not reside on the reserve. Furthermore, residence may be seasonal or periodic, e.g. when work contracts end or

begin. In this dynamic setting, who would best represent the “community”? From a clinical perspective, the interests of the patients are generally the most important. However, in keeping with bioethics and aboriginal research standards, I also had to consider the interests of members of the participants’ extended families as well as the wider reserve community.

At issue was the requirement of ensuring privacy and anonymity to individual participants as well as the community due to concerns that they would risk stigmatization based on publication about the genetic susceptibility to cancer among some people from the reserve. Gregory and Satterfield warn that “[i]n stigmatized communities, many of the strongest risk characteristics are those related not to residents’ own experience of a risk (e.g. the dread of health consequences) but rather to their experience of how they are viewed by others” (2002:352). On countless occasions, I have witnessed the potential for people in this community to face stigmas based on the limited understandings of outsiders about hereditary cancer and of aboriginal peoples and communities. For instance, the non-native people I spoke with during my fieldwork all asked whether aboriginal people were generally more susceptible to cancer. However, I often felt they were asking me for confirmation of a suspicion that already exists in the community, namely that *being aboriginal* is the main risk factor for cancer in the community, rather than having a hereditary mutation.

Aboriginal people in Canada already face stigmatization due to complex health problems (such as tuberculosis and alcoholism) and academic explanations of incidences of these diseases in aboriginal communities (Waldram, Herring, and Young 1995). If people feel additionally stigmatized based on a perceived link between cancer and their

aboriginal heritage—a heritage they may view as cultural, biological, or both—this may lead them to dismiss as irrelevant explanations of cancer as caused by genetic factors. One way to avoid contributing to this potential for stigmatization is conceal the true name of the community. However, by concealing the community’s identity, the reliability of the research may come into question. The level of concealment is also at issue here, because it is impossible to understand or assess the researcher’s interpretations without knowledge of the community context. Yet, those details are precisely what make the community’s identity important to conceal. Specifically, there is an increased chance that those who have prior knowledge about the cancers may be able to identify individual participants in the study, even when pseudonyms are used. Hence, in addition to the use of pseudonyms for all people, and places, I have tried to omit details that may identify the participants and their community.

## **THEMES**

A number of themes emerged from analysis of the interview data. Many of the statements and ideas express more than one theme, but because they are interrelated, I have merged them into three broad categories: 1) fears of cancer testing and contagiousness; 2) gendered illness; and 3) environmental factors. The views of these participants do not represent those of all community members; however, I believe they are diverse enough to give a sense of the varied ways many people are making sense of, and coping with, cancer and hereditary risk.

### **Fears of Cancer, Testing, and Contagiousness**

People express fears of cancer in a variety of ways in this community. Rachel—a participant with a strong family history of hereditary breast cancer who is not yet prepared to get tested—claimed that people at risk might not want to get tested because the perception is that everyone who gets tested ends up getting cancer. Even though she laughed at the logic, she admitted that even she felt that way at times, and said her philosophy is “what you don’t know won’t hurt you”.

Another female participant, Theresa, explained that her initial fears of genetic testing developed into fears regarding other areas of her health care:

*I tried to do it years ago like I was going through it all and then I just/ I don't know I got scared I guess so I didn't go anymore? I quit seeing the doctor for a while too because I was scared of my test results? I didn't want to go for my pap tests or... what do you call it... my mammograms? For a while, because I was afraid/ That's what I'm afraid of now too/ I was kind of glad that they cancelled my appointment for THIS month cause I'm just SCARED now because/ I don't know/ I'm scared they're going to find something on me now with the MRI...*

Isabel, a young parent who has not been tested for the hereditary mutation in her family told me that she has a has “a hard time” going for her “paps” because of fears about the

human papillomavirus (HPV) and its association with (non-hereditary or sporadic) cancer. She said that receiving reminder letters was good incentive to make, and keep, appointments.

Rachel pointed out another perception that may exacerbate the fear of cancer in the community, namely that cancer is contagious:

*There's too much of it. I almost started thinking it was like a cold, you catch it from somebody... YEAH! Cause, just different people, the way THEY got cancer... Well when they were diagnosed I guess it seemed like... When Olivia got cancer, her daughters or ONE of her daughters had cancer and then a few - quite a few years later her OTHER daughter got cancer/ and then SHE got cancer and then that daughter's HUSBAND got cancer...*

Theresa was also concerned about the possibility that cancer is like a virus:

*Theresa: I often wonder if it had to do with/ I don't know/ I guess with sex? That's what I wonder/ because I'm not really sure like how my grandmother/ what she passed on from/ if it was breast cancer/ and my mom and my two sisters too/*

*Natasha: When you say "sex" do you mean being male or female or do you mean having sex?*

*T: Having sex? yeah/ just I wonder if it had to do with just like the INFECTIONS or the VIRUSES [...] Like I think that's the only concern is wondering if that has to do with it/ and I don't know like how sexually active THEY were, but I know alot of... they were... in the old days alot of them were fooling around with each other TOO and I'm not sure if my mom was that way or my grandma....*

At a workshop on abuse, she learned that health problems manifest in the body in

locations where abuse has occurred:

*So it just kind of makes me wonder if it has to do with [sighs] stuff that has HAPPENED to you/ and then holding it in and if that's what causes it/ it's the STRESS/ and that's what they were saying/ it's the STRESS builds UP in you and it turns INTO something like CANCER or you get SICK or some sort of SICKNESS...*

A few people I spoke with also suspect that those diagnosed with cancer, or who perhaps suspect that they have cancer, may choose to reject treatment options based on perceptions that treatment was (at least in the past) worse than the disease itself. Gillian, a

breast cancer survivor who has a positive BRCA2 mutation status, noted her father's fear that he would die if he went to the hospital:

*They're just going to wait for something to happen and then that's when the decision gets made to do surgery or not/but I think he knows that if they give him surgery he's going to die/ because he'd have to go to [the nearest hospital] and he says "I know if I go [there] I'm not coming back home"/ but he's basing it on his other friends who went to [the hospital] and never came back alive/*

Given the relatively small size of the reserve, many people likely know of others who have received cancer diagnoses as an un-expected outcome of getting a genetic test or other surveillance testing such as a mammogram. That was how Emily, a woman in her fifties, received her hereditary cancer diagnosis:

*...then they were doing [...] mammograms in the hospital/ then I missed one year and so I went to the doctor and said "well, I missed a year" and I was sort of like scared I might have cancer or something/ scared to find out when I get cancer/ and he said "how about if I send you to [the town with the nearest hospital] And so they sent me to [the hospital] and that's where they found it/*

Sylvia also sought genetic testing when a relative diagnosed with hereditary breast cancer encouraged her to do so. Her test result was positive; she had "the gene". However, it was by having prophylactic surgery, and consenting to have her tissue tested, that she discovered she already *had* cancer.

### **Gendered Illness**

One anticipated finding of this study is that people seem more concerned about the risk status of women than of men. Despite men's lower risk of getting cancer if they have the hereditary mutation, male carriers may also pass on the mutation to their daughters and are at risk for developing other common cancers also associated with BRCA mutations. Emily—a breast cancer survivor who tested positive for the mutation and who is one of several daughters in a large family—reported that none of her brothers have gone through



genetic testing because they are “scared”, despite their daughters’ risks. Likewise, when I asked the only at risk male in the study if he would seek predictive testing, he replied:

*No. Because it’s mostly on the women’s side of the family, in my family? it seems to be most of the WOMEN/ none of the guys/ they just kind of pass away from accidents or age/ or doing something stupid/ I’m not gonna do anything stupid (laughs).*

The view that cancer only affects women in the community is evident in this exchange:

Isabel: *....so I’ve been thinking about this genetic testing...*

Natasha: *You’ve been thinking about it since you’ve had the baby?*

I: *Yeah, because my auntie Lorraine suggested to it to the WOMEN in our family? And it turned out to be positive for her/*

N: *Yeah... so you’re thinking, you’re considering getting tested then? What are you’re reasons for getting tested?*

I: *Um, because my Auntie Verna had it and my Auntie Lorraine had it and my Auntie Florence had it, and uh, my Auntie Gladys and my cousin Rhonda they have it but I don’t really know them that well? And there was a couple of ladies [on the reserve], they have it [...] so, just because it runs in our family on the WOMEN’S SIDE?*

Of the seven female participants with hereditary mutations, all mentioned the risks of their children or their siblings’ children as reasons for getting genetic testing themselves. Rosalie said that when she learned she had the mutation identified in her family, she responded: *I don’t know... just.... “Tell my kids! (...) I better tell me kids!”*. *So I told them, and they were gonna go get checked*. Likewise, while some of Alice’s relatives did not initially want “to know” about their hereditary risks, many have changed their minds because of children:

*People are just now becoming more aware since finding out that it’s hereditary? I know I was talking to some of my cousins and they said/ my nieces and cousins and some were saying they didn’t really want to know? And then later we talked about it again and they told me ‘well, they have children to think about’ so it’s not just ourselves/ we’re beginning to look towards the children/ what might happen when they grow up? Or maybe even BEFORE they grow up? Since it seems to be happening to young people.*

For some the fear of testing may far outweigh the sense of responsibility to children, particularly if the person at risk is male or has witnessed several family members have cancer:

*I know my other brother - he's two years older than me - he's still upset and sad at the same time. My brother James, he's pretty scared but I know he's gone back to work so I don't know how he's doing. My sister Eileen is -/ I really don't know how she is? So I don't know how she feels about the cancer. We did lose aunties and cousins too, so we've kind of been like WATCHING IT? We didn't know if it would happen to us actually, so we've just kind of been WATCHING I guess?*

Considering the reactions of her children to the knowledge she had the mutation, Rosalie admitted: *"I don't know if my son is gonna go get checked cause/ the mother of HIS daughter is his first cousin too/ she's my niece through my brother. She's also his cousin from his dad's side too..."*

Testing positive for the mutation provided some with a sense of relief regarding their risks for cancer, as though their genetics would diminish their individual responsibility if they were to get ill. For example, when I asked Rosalie what puts her most at risk, she replied:

*You mean like the gene? I just know that I [...] [have] the gene so therefore we're more at risk... I guess it would be that and then Hydro too/ you know, it's a GENE you INHERITED it/ where else would you get it? It's not put INTO you... I don't/ that's what I think/ that's not HER opinion (laughs and indicates to her younger daughter)/ A GENE is a GENE, there's nothing you can do about it. Unless you can go to a scientist and get it taken it out, other than that! I don't think so (laughs).*

For Theresa, and others, the confirmation that one has inherited a genetic mutation leaves people with conflicting ideas about cancer risk:

*Just having the gene I guess? Because of it being passed DOWN I guess? I just wonder like... just because of the past history of it kind of SCARES me and I wonder if it's going to happen to ME or my KIDS and/ I guess that's the only real concern I have because of how strong it is in the family history that I worry about it/ I try not to worry about it/ I often wonder like/ I don't know, "Where did it come from?" ... "Where did cancer ever come from and why is it killing our people?"*

## Environmental Factors

The question—“Where did it come from?”—is one that I heard repeatedly from people on the reserve. According to the participants in the study, part of the answer is environmental. Many attribute cancer to polluted water sources, PCBs from electrical transformers now used as tar for paved roadways, and the consumption of food (e.g. fish and berries) harvested in polluted areas. The presence of power lines in the community contributes to the perception that the number of cancer cases is higher than in other communities. One woman who felt the vibrations of power lines on her child’s body said this was “really scary”. Others said cancer was caused by something “around” though often unidentifiable.

Monica is a young woman at risk of having a hereditary mutation due to her mother’s positive status. Although her mother seemed satisfied with a genetic explanation of cancer in her family, Monica was not so convinced:

*I’m worried about getting cancer too/ I don’t take meds/ I don’t give my kids medicine [...] but otherwise I don’t go to see the doctor for anything/ I don’t bring my kids to the doctor either so/ the only thing other would be getting the cancer too, like actually GETTING cancer. [Having] the gene wouldn’t be as bad I don’t think? It’s just if it would go down to my kids too? Um, I don’t blame a gene for it, I blame [hydroelectricity]. I blame everything that’s AROUND...*

Monica’s perception that there is something “around” the Valley causing the cancers was also shared by a young couple I interviewed who are both very concerned about the incidence of cancer in their community. In Michelle’s words, there is “*something about around HERE/ cause around HERE everybody GOT it [...] compared to everywhere else in the [area]*”. According to Oscar, Michelle, and others, most of the people diagnosed with breast cancer seem to be living on one side of the reserve. People fear that the location Michelle refers to has contaminated water sources due to pollution from the

hydro towers. Importantly, residence patterns also appear to follow along family lines in the sense that individuals from similar “families” (such as adult siblings and their parents) tend to reside within the same subdivision of the reserve—though there are many exceptions to this. In addition, several people told me that the area of the reserve they currently lived on—or lived on in the past, or were moving back to—was the ancestral land of their ascendants.

The hypothesis that people in some parts of the reserve are at higher risk than others is difficult to confirm in part because members of households may change as people move to different locations on the reserve, or to another reserve, town, or city. This may explain why some people expressed contradictory views about the causes of cancer and the role of hydro towers and the railway. Despite fears that electromagnetic waves cause cancer, Theresa felt that this might not explain all of the known cases in the community:

*It concerns me alot because alot of the people that did have some cancer here DO live close to these big towers and all that/ like that's what concerns ME but then I think about it and my mom didn't LIVE here near these things and / yeah they lived way down the reserve/*

Another couple wondered, “*what else could it be?*” that is causing the cancer, yet denied accusations made against the power company by others.

Others appear more certain that the hydroelectric towers (and to a lesser extent the railway) are to blame for cancer in the community. Monica explained the power company’s role in causing cancer (and her miscarriages) as follows:

*Well it didn't start happening/ I don't think it started happening anyways until [the power company] moved in, that's when everybody started getting sick, that's when it was noticed/ so/ that's a lot of/ I noticed that a lot of the miscarriages happened HERE TOO/like when I lived up in [another community] there was no [hydroelectric] stuff up*

*THERE and I was fine up there but when I came back home that's when I lost the BABIES?*

Oscar refers to biological malformations as evidence of environmental hazards:

*O: It seems like [the power company] / whatever the/ they uh/ it seems like [the power company] dumps something on the lake once in a while? Cause one of our friends caught a weird looking fish one time/ so it was kind of strange to see THAT come out of our lake/*

*ND: So you guys know they're dumping stuff in the lake?*

*O: Well you don't catch a two-headed fish without SOMETHING going into the lake! (all laugh)*

When I asked Theresa where she picks berries and whether she would travel off the reserve for this activity she replied:

*NO but I haven't picked around here for a while because they were trying to say that [the power company] might have something to do with cancer so... and then I noticed that that's the only area where some of the berries grow BIG? so.... so I haven't picked around here/*

Likewise, Rachel remarked that "some people won't pick berries under their lines because they don't want to get cancer through the berries".

Perhaps due to her experience with the HCP and with cancer generally, Theresa is somewhat more ambivalent than others about the relationship between cancer and the environment and the perceived risks faced by her community:

*Theresa: ...I always think like "if it was linked to the [hydroelectric towers], why isn't there more people [who work for the company] dead? Why is it mainly just women?*

*Natasha: what do you think about that, that it's just the women?*

*T: I often think that it's caused by stress, that's what I think / because women take on a lot of stress (...) more than men? men don't / they brush it aside or whatever? like/ and I just that a real concern because/ it's only women/ like / even for the NON native it's just the women who have passed on from cancer TOO? And none of them worked for the [power company] either? So it makes me wonder like "where's it comin' from" that's... Cause, if it WAS then why aren't men getting affected? That's what makes ME wonder. Why is it only the women?*

Theresa was not the only person to comment on the effects of stress on the lives of women on the reserve. One 40 year old man, who is also the son of a women with breast cancer, remarked to me (as I was surprised by his age) that “all the men around here look young... it’s the women who seem to age much quicker”.

People expressed suspicions that other “environmental” or “lifestyle” factors are contributing to the cancers or complained about the abundance of conflicting information about cancer in the media. Dorothy summarized this confusion the best:

*The toxic stuff? I don't know/ I'm not sure where it all came from, if it all started with/ if it was actually here before? or if it just came here with [the power company] and [railway] / and of course SMOKING and DRINKING and EATING bad FOOD and (...) stuff that we probably never ate and drank before? I'm not sure/ like it could be all this/ everything together/ like when they were telling me about the CANCER gene/ something/ anything can sort of like trigger it off*

A mutation carrier herself, she further explained:

*I don't know if it was what CAME here or what was ALREADY here... and having that gene to START with/ like if it came because [of the power company and railway] way back.*

Dorothy recounts what she has learned about this complex hereditary disease, yet knowledge that her cancer is hereditary seems only to raise more questions. Similarly, Rachel insists that the hydroelectric towers pose a threat *because there's so much of it HERE and not in / it seems like there's more HERE than other reserves. [...]* And just *listening to my grandfather/ my great-grandfather when I was younger I never heard them talking about any cancer from a long time ago.*

In other words, the view that underlies concerns about environmental toxins from the railway and hydroelectric towers is that cancer is something that originated elsewhere and that it is something that the community's ancestors did not experience.

## DISCUSSION

Based on my interviews and observation, it appears that many people in the community believe they are at risk for developing cancer, regardless of any genetic ties to someone with a gene mutation. However, public health statistics on individual communities in the province are limited and challenging to interpret. Consequently, it is not possible to determine whether the actual incidence of cancer in this community is significantly higher than the provincial average. In general, women who have inherited a pathogenic BRCA2 gene mutation have a cumulative lifetime breast cancer risk estimated at 40-57% (Chen and Parmigiani 2007) compared to the general British Columbia population risk of 11%, or 1 in 9. There is also an estimated 13-23% lifetime risk of developing ovarian cancer. Males who have a mutation in the BRCA2 gene have a 6% lifetime risk of breast cancer and a two- to three fold increase of prostate cancer (compared to less than 1% and 12 %, respectively, in the general population (Breast Cancer Linkage Consortium 1999). Since this inherited cancer syndrome will affect multiple individuals within this small community, it is reasonable to expect that cancer anxiety is elevated.

Generally, fears of cancer mirror the multiple ways people in the community explain the causes of this disease (e.g. the showers, viruses, the environment, genetics). However, for people with known hereditary risk, fears are more complex and include fears of having the gene, as well as fears of *knowing* one has the gene. Hence some people take the approach that “what you don’t know won’t hurt you”). On the other hand, people may fear testing itself, along with the knowledge that testing provides. For example, “testing” could signify more than *genetic* testing, which could affect decisions



about various treatment and prevention that involve taking tests as well as intensify fears of cancer in the community.

Importantly, we cannot reduce these widespread fears of cancer to inclusive and interdependent notions of family and relatedness. Nor are they merely a subset of overarching worries about the effect of environmental degradation on community health. Instead, fears of cancer and of environmental contamination are two parallel issues for people in the community that we cannot understand apart from the historical context that they are both rooted in, and as I will suggest, may have come to symbolize. This is the context in which people at risk for hereditary cancer, and those who feel related to them, experience that risk. Below I discuss this experience of risk in terms of three aspects of everyday life on the reserve: the family, loss of family members, and the relationship between sense of place, community identity and colonialism. I hope to demonstrate that what is at stake for people in this community is not merely the probability of illness due to heredity, but of the possibility of imbalance (illness) to their social lives, relationships and community.

### **Hereditary Risk and Family**

The most common reason given for decisions to pursue genetic counseling or testing was that it would benefit the future health of children in the family. This is not a surprising finding. Studies regarding interest in susceptibility testing, decisions to undergo predictive or pre-symptomatic testing, and actual uptake for testing related to BRCA1 and BRCA2 and or HBOC generally have found risks for children to be an important motivating factor (Foster et. al. 2002; Hadley et. al. 2003; Glantz et. al. 1999; Lerman 1994; Lodder et. al. 1999). The differences among the participants in this study are that

concerns for children included one's own offspring as well as the offspring of one's siblings and other kin. The structure of First Nation families partly explains this emphasis on risks to the younger generation. If families are large, inclusive, and interdependent extended kin groups, then a mutation carrier worried about the health and genetics of her own children is likely to worry about the children of other siblings or close kin.

Historical and political factors that have an impact on social order and kinship are also relevant to the participants' emphasis on youth. For instance, many participants, who were primarily middle aged or older but included one young woman, spoke to me about the cyclical affects of "residential school syndrome" on their lives and today's youth, particularly with respect to alcoholism. The increasing number of aboriginal youth in recent decades, and the social problems they face, may also play a role in terms of goals for cultural continuity. Efforts to revitalize aboriginal languages and the cultural knowledge of elders may have the counter effect of creating positive self-identities among aboriginal youth who have high rates of suicide and school attrition (see Hallett 2005). Some scholars have noted the reciprocal needs between youth and elders in terms of mental health (*Swinomish Tribal Mental Health Project* 1991: 158) but I think the same may apply in terms of cancer and other illnesses. Children are significant because the cultural threads that reproduce intergenerational community relationships may be just as "at risk" as relatives of hereditary cancer patients.

As expected, gender plays a role in the way people understand hereditary risk for breast cancer, particularly in terms of *who* is thought to be most at risk, e.g. "it's mostly on the women's side of the family". Due to men's relatively low risk of developing breast cancer, they may be less motivated to pursue genetic testing (Dudok de Wit et al. 1996);

however, this does not lessen the risk of transmitting the mutation to offspring. Martin Richards observes that among women attending family history clinics for breast or ovarian cancer “an overwhelming majority have a maternal, rather than paternal, family history of cancer(s)” (1999: 561). He reasons:

Given that the initial recognition of families who may carry a pre-disposing mutation is through a family history, the relative absence of those with paternal histories indicates that a significant number of those at risk may not be seeking genetic counseling. This situation appears to arise through family (and sometimes professional) beliefs that emphasize mother–daughter transmission of the risk of breast and ovarian cancer and may fail to recognize that (largely) ‘female’ diseases can be silently inherited through a father. [Richards 1999: 561]

Rosalie’s pedigree and description of her son and brother’s reluctance to be tested are vivid examples of how the hereditary breast cancer risk may be “silently inherited” through males in the community. There is a 50 per cent risk that, like Rosalie, her brother and other siblings have inherited the hereditary mutation, it is not clear if their deceased mother also had the mutation. Rosalie’s children also have a 50 per cent risk of having the gene mutation, as do the children of her siblings. The fact that her son and her brother’s daughter are married and have a child together complicates the calculation of risk in clinical terms. Since both parents have a 50 per cent risk of inheriting the mutation from one of their parents, Rosalie’s granddaughter has a 75 per cent a priori chance of having the mutation. If only one parent has the mutation, then the granddaughter’s risk of inheriting it is 50 per cent and if neither parent has the mutation then the risk of inheritance is zero.

Rosalie’s family example also exemplifies how genetic knowledge is often contested within families, with some people refusing “to know” their risks as a right of choice and others determined to share knowledge of risk out of obligation. Like

Hallowell (1999) I found that most women were driven to seek genetic testing by their sense of moral responsibility regarding the cancer risks and health care of other kin. The women in her study felt it was their duty to convey risk information to family members, particularly children, and at times to convince them of their own need to be tested. Such views, observes Hallowell, are couched in the broader generalized rhetoric around the new genetics and individualized responsibility for overall health, despite any uncontrollable genetic factors. Nonetheless, the sense of moral responsibility felt by the women I interviewed may be unique compared with non-aboriginal women because of the sense of social responsibility that already exists in aboriginal communities.

Hallowell (1999) argues that women's sense of responsibility regarding risk management in their families is rooted in gendered discourses about women's caregiving roles, and ironically, works counter to the ideal of choice and independent decision-making it is modeled on. In actuality, "this approach [...] does not take into account the social locations or life circumstances of various individuals. It fails to ask whether it serves the best interests of everyone to be informed about their genetic risk status" (D'Agincourt-Canning and Baird 2006: 119). The everyday "life circumstances" of the women in this study may be relevant for understanding their perceptions of hereditary risk, particularly with respect to their roles as women and caregivers in the community. Yet, the roles of some women may be more visible than the roles of women elsewhere. Aboriginal and feminist scholars are only beginning to understand the complex relationships aboriginal women had with colonialism and their affect on gender roles (Miller and Chuchryk 1996; Kelm and Townsend 2006).

Theresa hypothesized that more women than men get cancer because they shoulder more of the domestic burdens in the community, particularly with respect to health. Caring for the young and the elderly is part of the work of many aboriginal women, although healthcare practitioners do not always validate this role (Browne and Fiske 2001:136). Yet, we should not assume that caregiving singularly defines the gender roles of women in this community—either today or in the past. For instance, Miller (1989) found that Upper Skagit women’s role in the 1980s shared many characteristics with the documented role of women in the pre-contact period, despite changes brought on by colonialism. Focusing on women’s political role, he argues that greater gender flexibility for female (but not male) roles left some women better able than men to cope in a post-contact world (Miller 1989: 180).

Arguing that federal practice and policies in the 1970s and 1980s differentially affected First Nation women, Fiske (2006) explains how values of the inter-dependent extended family permitted the kind of role flexibility that Miller identifies:

Cooperation and sharing enhanced women’s social mobility. Collective responsibility for child care, for example, allowed women to pursue wage employment and education away from their communities. Similarly, pooling a range of subsistence goods and cash meant that women who were absent from seasonal subsistence production, whether they resided elsewhere permanently or only occasionally, could expect to share domestic provisions. Through collective labour and mutual support, women were relieved from performing domestic services for men and were protected from systematic economic dependence upon them. [Fiske 2006:344]

Importantly, Fiske acknowledges that the gains made by aboriginal women were relative (based on economics) and paradoxical in that they still face health and social problems related to poverty (2006:345). She also points out that women often care for their own children, as well as the children of male kin, and their grandchildren.

Both Miller's and Fiske's arguments raise questions about the gender roles of women in the community where I did this research. Though women's political work did not surface as a major concern, several women in the study had experience and roles as leaders in the community in their work in the schools, the community health centre, and the band. Although men may share these roles and worry equally about the community, women's expanded roles may mean they carry more of the stresses of the community, which ultimately affects their health. Paradoxically, the same responsibilities that burden women regarding family and community health (e.g. sharing knowledge of hereditary risk), may be perceived as risk factors for cancer and other health problems they want to prevent.

In her study of patients at a breast cancer genetics clinic, Sahra Gibbon concludes that "the work of patients in pursuing certain 'at-risk' identities reproduces a particularly geneticized reading of family history and relatedness – a practice that is intimately tied to the investment, hope, and promise of predictive medicine" (2007: 147). In aboriginal and other underserved communities where accessible public health services may be lacking, it may not be the promise of *predictive* medicine but the promise of medicine or improved health care that motivates people to pursue genetic knowledge. At the same time, Rosalie's pedigree demonstrates that the geneticization of one's genealogy may be insufficient for identifying those at risk. Since we know there is a pathogenic mutation, a high degree of interrelatedness would mean that many people could be carriers. However, without accurate *genetic* family histories, individuals may be unaware of their biological relationship to spouses or partners. Children of these unions would each have a 75 per

cent chance of inheriting the mutation, as well as an increased risk of developing the disease.

Despite the growing knowledge that genetic predisposition to cancer may in some cases be quite high, few people talked about cancer as a hereditary illness. Most people described cancer as omnipresent, and feared that exposure to environmental toxins puts the entire community at increased risk. Furthermore, while the experience of hereditary risk is more relevant to those who are close with family members who have a positive status, everyone in this interdependent community experiences cancer. For this reason, we must separate concerns about hereditary breast cancer from fears of cancer in the community.

### **Cancer and the Experience of Loss**

The perception that cancer threatens the entire community reflects the experience of cancer on the reserve. The relatively small size of the community and the view that “everyone here is related” means that cancer’s tragedies, challenges and burdens affect people directly or indirectly. The loss of “aunties” and “cousins” to this disease has deeply affected many people in the community. To symbolize their grief and the memories of those who died, a group of individuals concerned about links between cancer and the environment erected a large pink cross on the hill overlooking the main hydroelectric towers and facilities. At the foot of the cross, they placed smaller crosses, each representing a specific person’s death. Their objective was to have as many crosses on that hill as people who have died of cancer. Not everyone in the community agrees that raising these crosses was a good idea, particularly if the goal is to blame the power company for cancer incidence. Regardless, the symbolism of the crosses expresses

resistance to the power company's presence and calls attention to the impact and significance of cancer and of *death* for people in the community.

Death and funerals were often topics of conversation during the course of my research because family stories of cancer included many accounts of people who had died from the disease. However, the genealogies also included stories of fatal fishing expeditions, house fires, and car accidents, preventable deaths common to many aboriginal communities in Canada. Likewise, my post-fieldwork phone conversations with the woman I had stayed with usually included updates about new cases of cancer, "so-and-so's" treatment, another person in hospital, or another funeral. During one particular conversation, she painfully recounted to me the number of funerals she had been to in the weeks prior. Notably, few of these deaths were cancer related. It made me wonder how the loss of relatives by other causes might influence the way people perceive cancer incidence in the community.

O'Neil's (1996) study of depression among Flathead Indians sheds light on what the significance of death might mean for perceptions of cancer risk. She explains how Flathead people use death as an opportunity to teach and encourage socially responsible behaviour in the community by transforming their grief and loneliness into compassion and pity (1996: 91-93). According to O'Neil, "[g]rief is dangerous because it can produce a mournful sense of abandonment, and the resulting tendency to isolation requires the vigilant efforts of others to redress" (1996:81). Authors of the *Swinomish Tribal mental Health Project* similarly claim that family members who mourn excessively can die from their grief "since the spirit may pity them and take them along to the land of the dead" (1991: 160).



General anxieties about mortality by causes including, but not limited to, cancer may exacerbate fears about cancer in this community. If there is a general sense of loss in the community due to a variety of factors, cancer may be just one issue among many that individuals and families face. Further, people may fear the loss of the family and friends (to death or grief) as much as they fear their *own* mortality. As O’Neill suggests, intergenerational relations may be significant in this respect:

The loss of a family member is almost always difficult, no matter how distant the relation. This emphasis on depth of grief for all family members is merely another facet of the importance of family in the Flathead way of life. To lose a family member is to come face-to-face with the possibility of being alone, the possibility of having no one to care for you. [O’Neill 1996: 99]

The loss of loved ones can potentially damage the reciprocal social relations necessary to ensure the health and well-being of the entire community. This may be one reason why people are so deeply concerned about the future health of young people in the community.

### **Cancer, the Environment, and Sense of Place**

Despite the known genetic risks for relatives of the women who have tested positive, the common concern among participants is that toxins in the local environment are increasing the chances that people in the community will develop cancer. Most people think that the location of the community, or the place itself, is to blame for the cancers in the community. They argue that damage to the natural environment has caused plant and animal life, which are still very much a part of the community’s subsistence, to become toxic. Nonetheless, many people (and not just those with familial risks due to family history) held contradictory views regarding the community’s fears about environmental risks. Essentially, they incorporated both genetic and environmental explanations of

cancer into their accounts of cancer in their families and community, seeming undecided as to which posed greater risk.

This ambivalence may reflect differences in priorities regarding hereditary risk. Cox and McKellin contend that “the relevance of risk” for people with Huntington’s Disease is “fluid and contingent: information is, at certain critical junctures, given a high degree of relevance, while at other times, it has much less importance” (1999: 628). This is because:

Participants’ perceptions of risk change during the course of testing, as individuals move between the real world of everyday life and the clinic. The clinical focus on a particular issue highlights the familial disease, when in fact other concerns, such as the nonhereditary disease of another family member, may be of greater concern at home. [McKellin 2001:32]

Several people I spoke with indicated that they or family members had chosen not to seek predictive testing partly because other health, family, or social concerns were more pressing. More importantly, the fact that everyone in the study expressed worry about environmental influences on cancer indicates that this is the prevailing concern in the community.

Fears of cancer and the relationship between this disease and pesticides in our food, pollution in our air, and chemicals in our water are pervasive in North America. Many have linked this chemical burden to the majority of (non-hereditary) breast cancer. However, to confuse or equate general societal and global angst about cancer with the fears expressed by those in this study would only serve to trivialize this community’s long-standing environmental concerns. Frustrations about environmental degradation existed long before the HCP identified a hereditary mutation among members of the reserve, but these frustrations include concerns about social and cultural impacts as well.

Alice, an elder in the community who also has a hereditary mutation, claims that while the power plant brought jobs and temporary wealth, it also permanently altered social relations:

*It ISN'T like you know in the early community people used to GO VISIT each other. Even before cars I could remember horse and wagon coming to visit. I was really small but I remember alot of stuff since maybe TWO. And I could remember families visiting each other, sharing their FOOD. That doesn't happen anymore.*

In addition to their effects on the environment and community health, Alice believes the train and rail companies had a direct impact on community structure and the way people relate to one another. Concerns about environmental risks appear entwined with how participants understand the historical and present political relationships of their community, as well as the relationships between people and place.

Recent research indicates that sense of place is central for the way people view environmental risks (Wester–Herber 2004; Masuda and Garvin 2006; Jardine et. al. 2009). From the perspective of the individual, place is central to self-identity construction (Wester-Herber 2004) while in terms of collective groups, sense of place influences perceptions of risk, including how and why people augment or attenuate risks (Masuda and Garvin 2006). Jardine and colleagues (2009) argue that place is significant in how people view health risks, having more of an influence than even gender. Basing their argument on research with aboriginal communities, they maintain that researchers must examine risk perspectives “within an ‘ecological’ context which considers the interconnected social, economic and cultural milieus that define different communities and different cultural groups” (Jardine et. al. 2009: 204). The “social environment” they describe are health concerns that echo many of the concerns of people I interviewed,

particularly with respect to community health, children, and alcohol (Jardine et. al. 2009: 218).

One aspect of the social environment they describe may need more emphasis, however; namely, the relationships among family and community members. Social *relationships* may be significant for understanding views of health and environmental risks, particularly in aboriginal or First Nation communities. For instance, different generational views might explain in part the various ways that people in this community are grappling with genetic information about breast cancer risk. The power company once employed many elders in the community, so some elders I spoke with cannot understand why so many of the younger generation blame the company for all the cancer problems. Perhaps one reason why people like Alice and Rosalie emphasize genetic versus environmental risks is that it allows them an escape from the scrutiny of younger community members who may blame them for allowing outsiders to maintain so much control over ancestral lands.

Garro (1994) also found generational differences in how people from the Anishinaabe reserve explained the cause of diabetes, although these differences manifest in reverse. She loosely categorizes their accounts of diabetes along a continuum of two explanatory models: “the contaminated food model” and the “the biomedical teachings model” (1994: 42-43). She reports that the mean age of individuals who identified quite strongly with the latter model would place them in a generation that is not only younger than the proponents of the first model, but one that would have witnessed more diabetes during their lifetimes. In other words, though younger people in my study tend to emphasize what is similar to Garro’s contaminated food model, in Garro’s study it is the

older generation that does this. Likewise, it as the older people I interviewed that emphasized what appears like a biomedical teachings model, while in Garro's study the proponents of this model were relatively younger. The reason for this contrast is not clear though I suspect it may have something to do with the nature of hereditary cancer, and perhaps age of onset, as well as its impact on community risk perceptions.

The obvious difference between my own research and Garro's study is that diabetes is not a genetic illness in the same way that hereditary breast cancer is. Nonetheless, like the Anishinaabe, most participants in this study seemed to view cancer as a recent phenomenon in the community. In the words of one middle-aged woman I interviewed, "*just listening to my grandfather, my great-grandfather... when I was younger I never heard them talking about any cancer from a long time ago*". As Garro points out:

By blaming the individual, a biomedical perspective excludes the broader social context of the disease. Yet, such an explanation does not ring true for many of those interviewed, who, over time have observed increases in the number of community members diagnosed with diabetes. (Garro 1994:45)

Likewise, a question implicit in many interviews was what caused the gene change *in the first place*. So, even if people believe that a hereditary mutation is a factor of causation in many (if not most) cases of cancer on the reserve, the question 'where did *cancer* come from?' may more accurately mean 'where did the *hereditary mutation* come from?' Dorothy alludes to one possibility, namely that environmental toxins emitted by the hydroelectric power lines and the railway caused that cancer – or perhaps even the mutation.

Reviewing research related to environmental stigma, Wester-Herber (2004) states: "The image of stigma can come from a critical event, or a culmination of events, and can

be reinforced by such things as direct experience with the environment and reports in the media” (2004:111). While it is not clear that the First Nation people in this study have experienced environmental (or genetic) stigma, I believe that their “direct experience with the environment” has the effect of reinforcing other aspects of their social identities. Locating depression among Flathead Indians as part of the pan-Indian discourse about identity, O’Neill (1996: 8) observes that “depression in individual narratives often resonated with one hundred and fifty years of loss and betrayal and the moral imagination with which Flathead Indians strive to make meaning out of that history.” I would like to suggest that cancer and cancer risk in this community resonates with a similar history as well.

The meaning of cancer reflects the participants’ experience of colonialism, as well as the experiences of their ancestors and descendents. This experience is deeply rooted in their sense of place and relationship to the environment, which is their ancestral territory. In their struggle to comprehend why *their* people are afflicted with cancer, cancer becomes a contemporary symbol of colonialism and a reminder of injustices aboriginal peoples have experienced since their ancestors’ first contact with Europeans. These experiences include policies and practices intended to abolish aboriginal languages, cultures, and ways of thinking and being. Masuda and Garvin (2006) contend that “risk perceptions were not isolated within the minds of individuals [in their study], but manifested as threats to shared ‘ways of life’ that included people’s sense of belonging and well-being in the community at large” (2006:447). If aboriginal well-being and social relations are connected, people may view cancer as a symbol of colonialism because, like

colonial practices, this disease threatens the physical health of individuals at risk and therefore the cultural health of the community.

## CONCLUSION

Following the availability of BRCA1 and BRCA2 testing in the 1990s, many studies have focused on the nature, experience, and perceptions of hereditary risk both in dominant social groups and specific ethnic groups (Chavez et al. 1995; d'Agincourt-Canning 2001; Gibbon 2007; Koch and Svendsen 2005; Rajaram and Rashidi 1998; Salant et. al. 2006; and Svendsen 2006). Rajaram and Rashidi (1998) explored the relationship between women's cultural explanatory models and the use of genetic screening among minority women in the United States. Chavez et al. (1995) found that the cultural model that Mexican and Salvadorian U.S. immigrants used to explain breast and cervical cancer risks gave priority to factors (like breast trauma) not considered high priority in the biomedical model used by physicians in their study. Together these studies highlight a tendency for people to perceive and evaluate hereditary risks according to their specific cultural assumptions and social contexts, rather than in clinical biomedical terms.

Many of the views of women and men in this study appear similar to those reported in other studies of hereditary risk, yet are distinctive because they speak to a history of colonization, systemic marginalization, and most importantly, survival. The role of women is significant in this respect, because women—*healthy women*—are core in the interdependent family system that is central to the everyday functioning, health, and prosperity of aboriginal communities. Fear of cancer is common in North America, however, and it is equally common to prioritize the risks of women over men for hereditary breast cancer. Nonetheless, the prioritization of women's (and children's) risks in this community may reflect gender roles and the interconnectedness of intergenerational family relations.



Aboriginal family dynamics are significant because they provide a new perspective on relatedness and what bioethicists call “genetic responsibility”. The inclusion of nieces and nephews in some women’s claims of responsibility challenges the observation that: “Women with young children may experience more anxiety than women without or with grown up children, because of the threat of leaving young children behind if they developed cancer and died” (Foster et. al. 2002: 912). If caregiving is shared with others (albeit other women) in aboriginal communities, then women from at risk families may worry about the children of other kin as much as their own. Likewise, childless women who are caregivers may share the anxieties regarding children (and kin) that accompany the identification of hereditary risk.

Fears of cancer may be elevated relative to actual risks because people experience cancer within a broad web of complex health and social problems already affecting the community. These problems are determined in large part by the socio-economics and colonial history of the community, which includes their relationship with the medical establishment. Browne and Fiske (2001) find that many First Nation women feel that their health concerns are dismissed by the healthcare system they encounter, citing one example where a woman was sent home from the hospital only to die later in her home (2001:134). Their finding that “invalidating encounters” often characterize aboriginal healthcare raises questions about how perceptions of the medical system in British Columbia may contribute to fears of cancer in this particular community. Concerns about morbidity, and the cultural significance of death among many First Nation people, may also intensify fears of cancer.

The relations of family and kin may have clinical implications as well as influencing perceptions of risk. A history of complex social relations may mean that many people in this community are mutation carriers and therefore at risk for cancer related to the BRCA2 gene mutation. Conversely, if families make assumptions about relatedness even if the relation cannot be demonstrated biologically (as with adoption), then those with close social ties may perceive their risk of developing a disease to be much higher than it *is* based on genetic ties.

A study by Simchoni et. al. (2006) examines the influence of birth cohort and cancer site of index case on breast and ovarian cancer risks among Ashekenazi Jewish women with positive mutation statuses. They conclude that although it is less likely to find familial clustering of cancer site in families with recent immigration histories (due to the lack of shared environment) it is still possible that nongenetic familial effects (e.g. the environment) play a role (Simchoni et. al., 2006: 3772). Importantly, my analysis does not verify or reject the community's claims about environmental impacts, however I hope it will underscore the urgency of their concerns about environmental toxins. For, if we subscribe to the "two-hit" model, individuals BRCA2 mutation carriers who are additionally exposed to environmental toxins could be at even greater risk of developing cancer.

Finally, the relationship between aboriginal people and place may be central for how people in this community view their risks for cancer – including their hereditary risks. This is because sense of place and relationships with the environment (both natural and spiritual) are central to aboriginal identities and ways of knowing and being in the world. The community's colonial history influences how people view the environment

because this history includes struggles over the control of territory and the management of local resources. People in the community experience cancer as part of this relationship with place and the environment because the health of the community is very dependent upon the health of people, land and resources. Since many people believe that the environment must play some role in the incidence of cancer in the community, they do not understand cancer simply as a hereditary illness that affects individuals and families. Rather, they view cancer much like colonialism—as an overarching threat to the entire community.

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<sup>1</sup> I use “Interior Salish” to refer to the geographic location of the reserve, and the cultural and linguistic heritage of the people, though this is not the term they use for themselves. I do this to avoid revealing the identity the community.

<sup>2</sup><http://www.bccancer.bc.ca/HPI/CancerManagementGuidelines/HereditaryCancerProgram/GeneticTesting.htm>; accessed July 6, 2009.

<sup>3</sup> Additionally, I reviewed select medical information of participants who had granted permission for me to do so. This enabled me to verify the mutation status of the individuals who had received testing and permitted me to view their health records, as well as compare the clinical notes regarding family and medical history with my own. This process was instructive, but for the purpose of the thesis it served mainly for clarification.

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