Living at-Risk for Hereditary Breast Cancer: The Experiences of at-Risk Unaffected Women Who Live in Families Where a BRCA Gene Mutation Could Not be Found

by

Andrea Dawn Schroeder

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ABSTRACT

Harmful mutations in the breast cancer 1 and 2 genes (BRCA1/2) and other breast cancer susceptibility genes are thought to account for less than 30% of familial breast cancer cases. Many affected women (those with a personal history of breast and/or ovarian cancer) who undergo BRCA1/2 genetic testing will be advised that a mutation was not found. Despite the absence of a genetic mutation, both affected and unaffected (those without a personal history of breast and/or ovarian cancer) women living in these families may still be considered to be at an elevated risk for hereditary breast cancer (HBC) on the basis of their family cancer history alone. Similarly, these women may be asked to consider some or all of the risk-management options offered to women who test positive for a known harmful mutation. Little is known about how living with risk for HBC is experienced by at-risk unaffected women who live in BRCA mutation negative families.

The focus of the present study was to understand how risk for HBC impacted the day-to-day lives of unaffected women who live in BRCA mutation negative families. van Manen's hermeneutic phenomenological approach was used to uncover meanings within the experiential descriptions the participants provided. Two to three conversational interviews were conducted with nine women who were between 25 and 58 years of age. All of the participants were being followed by experts at a hereditary breast and ovarian cancer (HBOC) clinic bi-annually; had a projected lifetime risk of at least 20% for developing breast cancer; had not undergone genetic testing; and were aware of an uninformative negative BRCA1/2 genetic test result in the family.

Engagement in phenomenological reflection with the participants regarding the four life existentials (lived time, body, space, and relations) revealed "Moving In and Out of the What-Ifs" as an overarching multi-layered essence. An essence refers to the nature of something that

makes it what it is. Nine sub-themes interconnected with “Moving In and Out of the What-Ifs”. They were: “Just Moving Along: Living a Normal Life”, “Moving into those Dark Spaces”, “The Body Knows”, “Is there Something Wrong with Me”?, “Markings in Time”, “Living in the Moment”, “Indecision Within the Extended Present”, “Being Cared-For”, and “Keeping Me Grounded”.

All of the participants voiced that they spent most of their time in a normal life space where they got on with and enjoyed their lives with an awareness of their risk for HBC in the background. However, certain events or markings in time shifted the participants into dark what-if spaces where they confronted their mortality and experienced anxiety and/or fear over their risk for developing HBC. For many participants it was the close and supportive relationships they had with healthcare providers, family members, and friends that pulled them out of those dark spaces. Additional findings suggested that some of the women felt their concerns about their risk for HBC were not taken seriously by some healthcare providers. Not having their risk taken seriously caused frustration and the feeling that they were outsiders. Some of the women also voiced how some non-medical people in their lives equated their at-risk status to being unhealthy. Although these women referred to themselves as being healthy with risk for HBC, hearing comments from non-medical people that made them feel like they were unhealthy sometimes made them question the state of their health.

Thus, the study findings provide a rich understanding of possible ways in which unaffected women may experience living with risk for HBC. These understandings may inform healthcare professionals as they engage in dialogues with other women about living with this risk. For example, living with HBC risk may impact the way a woman experiences time. Some women may direct their energies to what they can experience and enjoy in the present rather than

putting things off into the distant future. Additionally, the findings highlight a need to examine gaps in healthcare professionals' knowledge regarding risk for HBC. There is also a need to explore how knowledge gained through predictive medicine impacts public perceptions of the term "good health".

PREFACE

This thesis is an original work by Andrea Dawn Schroeder. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board – Health Panel. Living at-Risk for Breast Cancer: The Experiences of Unaffected Women Who Live in Families Where a BRCA Gene Mutation Could Not be Found. Pro 00047026. May 20, 2014.

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I wish to start by thanking the wonderful and courageous women who participated in this study. The sharing of their stories touched me in ways that I could never have imagined. I learned a lot from these women and hope that the meanings conveyed in their stories will touch others as they get to know these women through this textual representation of their experiences.

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Due to unforeseen circumstances, as I embarked on the recruitment stage of my research, my supervisor changed to Dr. Wendy Duggleby. Wendy, I am forever grateful for the support and steady guidance you offered throughout the recruitment, analysis and writing stages of this project. I especially hold fond memories of our meetings to talk about the findings, the work we did together on your research projects, and the opportunities we had to get to know each other outside of academia. I always felt a positive synergy between us. To Dr. Brenda Cameron, I have fond memories of you calling me into your office for impromptu chats about phenomenology and how my research was going. Through our informal talks and course work on the philosophical nature of nursing, your beautiful way of communicating philosophical beliefs about ways of being-in-the-world opened my mind to new perspectives in relation to the human experience that I will hold forever. To Dr. Barbara Krause, I am indebted to you for your

willingness to bring me into your clinic consultations as an observer to gain an understanding of some of the issues women living with risk for hereditary breast cancer may face. I am also grateful for the time that you took to answer my questions about genetic testing and the thorough critiques you provided in relation to the quantitative literature I reviewed about BRCA genetic testing and breast cancer management options.

To my family and friends, I could not have seen this project through without your support and thoughtful words of encouragement throughout this journey. I especially wish to give thanks to my husband Dave and my daughter Anna. I thank you both for sharing in the excitement and passion I felt about this research and for helping me to stay on track during times when I struggled to see the light at the end of the tunnel. In closing, I give thanks to all of the people who made my PhD experience a memorable and enjoyable journey.

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CHAPTER 1 – INTRODUCING THE THESIS

Coming to the Study

In the first half of my journey as a doctoral student, I struggled with the decision to pick a research topic for my dissertation. *Find a topic you have passion for* were valuable words from my supervisor that hung in the space between my thoughts and the paper and pen I used to capture ideas. Although my background in public health nursing influenced my earlier decision to study childhood obesity prevention, it was my personal experience with breast cancer in the early part of my studies that aroused a passion in me to learn about the experiences of other women coping with breast cancer.

As I immersed myself in readings about the history of breast cancer, breakthroughs in medical science, and the experiences of women coping with this disease, I found myself drawn to research that explores the experiences of women who are at-risk for hereditary breast cancer (HBC). During my career as a public health nurse, I worked on health promotion and prevention projects in breast health. At that time, discussions on genetics and breast cancer were kept to a bare minimum. I believe that this will certainly change as more discoveries are made in breast cancer genetics. This belief was further strengthened when the Associate Dean of Graduate Studies Faculty of Nursing asked me if I knew of a genetics nurse who could write a section on genetics in a medical nursing textbook. I don't recall learning about genetics when I was a nursing student. As I read broadly about different aspects of breast cancer genetics, I started to think about how important it is for nurses and other healthcare professionals to understand how this information impacts the lives of those for whom we care.

Breast cancer genetics is a unique area in predictive medicine that provides women, who are considered high risk for a hereditary genetic mutation in one of the breast cancer 1 or 2 genes

(BRCA1/2), an opportunity to undergo testing for specific deleterious mutations that have been linked to high incidences of breast and ovarian cancer (Miki et al., 1994; Wooster et al., 1995). Women who test positive for a deleterious mutation in one of the BRCA1/2 genes have an estimated lifetime risk for breast cancer that ranges from 40 to 85%. Additionally, carriers of a deleterious BRCA1 mutation have a lifetime risk for ovarian cancer that ranges from 25 to 65% whereas those who test positive for a deleterious BRCA2 mutation have a lifetime risk for ovarian cancer that ranges from 15 to 20% (Canadian Cancer Society, 2015). Mutations in the BRCA1/2 genes are autosomal dominant (which means that the inheritance of only one copy of a deleterious mutation is necessary to predispose an individual to cancer) and have high penetrance (which means the chance of a person developing the disease is high) (National Library of Medicine (US), 2015). This information can be quite useful to women, who test positive, as they consider risk-reducing surgeries, chemoprevention agents, and intensive surveillance programs.

However, it is estimated that deleterious mutations in the BRCA1/2 genes account for approximately 15% of familial breast cancers, whereas deleterious mutations in the BRCA1/2 genes and other rare highly penetrant breast cancer susceptibility genes (PTEN, TP53, CDH1, and STK11) collectively account for up to 25% of familial breast cancer cases (Shiovitz & Korde, 2015; Stratton & Rahman, 2008; Antoniou & Easton, 2006; Walsh, Casadei, Coats, et al. 2006). An additional 2 to 3% of familial breast cancers are linked to deleterious mutations in rare moderate penetrant genes that include: CHEK2, BRIP1, ATM, and PALB2 (Shiovitz & Korde, 2015; Stratton & Rahman, 2008). Therefore, many affected women (those with a personal breast and/or ovarian cancer history), who undergo genetic testing will receive a negative result for a deleterious BRCA1/2 gene mutation.

Despite the absence of a known harmful genetic mutation, these women and the unaffected women (those without a personal breast and/or ovarian cancer history) in these families may still be considered at-risk for HBC on the basis of their family history alone. Given that women who live in these hereditary risk families may consider some or all of the risk-management options offered to women with a known deleterious mutation, it is surprising that little is known about the experiences of these women – especially at-risk unaffected women who cannot undergo genetic testing due to the absence of a mutation in the family. I started to wonder how unaffected women living in these BRCA1/2 mutation negative families experience living with risk. An in-depth understanding of what risk means to at-risk unaffected women and how they cope with it is useful for it will inform the practices of healthcare professionals. Thus, for this research I explored the experiences of at-risk unaffected women who live in families where BRCA1/2 genetic testing in an affected family member was negative and considered to be uninformative.

Purpose of the Study

The purpose of this study was to explore how unaffected women experience living with hereditary risk for breast cancer in the absence of a known BRCA1/2 genetic mutation in the family.

Research Question

1. How do unaffected women with at least a 20% lifetime risk for breast cancer experience living with risk when a BRCA1/2 genetic mutation has not been found in the family?

Significance of the Study

Of all breast cancers, about 5% are associated with deleterious BRCA1/2 genetic mutations (Canadian Cancer Society, 2015). Certain personal and family history patterns for breast/ovarian cancer point to the possibility of there being a genetic explanation for the number and/or clustering of familial cases. When a genetic mutation is suspected, an affected woman is offered genetic testing to detect certain mutations in specific breast cancer susceptibility genes. Although women are usually tested for the more commonly identified susceptibility genes - being BRCA1/2 - mutations in several rarer genes such as the CHEK2, TP53, PTEN, CDH1, STK11, ATM, PALB2, and BRIP1 genes can also increase a woman's risk for inherited breast cancer. Collectively, it is estimated that deleterious mutations in the BRCA1/2 genes and other known breast cancer susceptibility genes account for less than 30% of hereditary breast cancer cases (Shiovitz & Korde, 2015). This implies that a mutation in one of the known breast cancer susceptibility genes will not be found in a majority of individuals who undergo genetic testing.

To date, very little research has focused on the experiences of at-risk unaffected women who live in families where genetic testing for a BRCA1/2 mutation in an affected relative was negative and considered to be uninformative. In one study, Geirdal et al. (2005) compared the anxiety and depression levels in a group of BRCA1/2 gene mutation carriers (N=68) to a group of unaffected women living in BRCA mutation negative families (N=176). Anxiety and depression levels were higher in the group of unaffected women living in BRCA1/2 mutation negative families. In another study, Vos et al. (2011) identified low participation rates in breast cancer surveillance (36%) and risk-reducing surgeries (8%) in a small group of untested at-risk female relatives (N=12) living in families where a BRCA1/2 genetic mutation was not found in an affected relative. Although the sample size in Vos et al's study was small, the rates for

participation in breast cancer screening programs and risk-reducing surgeries were considerably lower than the at-risk female relatives (N=27) living in families where an unclassified variant was identified in an affected family member (Vos et al.).

Thus, the preceding studies raise questions as to how risk is understood and experienced by at-risk unaffected females when they learn that a mutation could not be identified in an affected family member. The aim of the present study was to explore how unaffected women, who are not eligible for genetic testing due to the absence of a deleterious BRCA1/2 mutation in the family, experienced living with risk for hereditary breast cancer. The insights from this study equip healthcare professionals with insights about their experiences that may be explored within practice settings, applied to changes in policy and education, and be used to direct future research inquiries.

List of Abbreviations

BRCA1	Breast cancer susceptibility gene number 1
BRCA2	Breast cancer susceptibility gene number 2
HBC	Hereditary breast cancer
HBOC	Hereditary breast/ovarian cancer
PBM	Prophylactic bilateral mastectomy
PPV	Positive predictive value
RRSO	Risk-Reducing Salpingo Oophorectomy
TVU	Trans-vaginal ultrasound

Definition of Terms

Absolute Risk. Absolute risk refers to the likelihood that an individual will experience a medical event. An individual's absolute risk is expressed as a percentage that is derived from a ratio. For example, in a population of individuals over the age of 75 years taking ibuprofen for arthritis, the absolute risk for an individual to experience a stomach bleed is calculated as follows: the percentage of people over the age of 75 who take ibuprofen and experience a stomach bleed is divided by the number of people in a group of individuals who are taking ibuprofen and could experience this event (Agency for Healthcare Research and Quality, n.d.).

Affected. In this research project the term affected is used to refer to individuals who have a personal history of breast and/or ovarian cancer.

Autosomal Dominant. This term means that only one copy of an inherited gene mutation is necessary to predispose an individual to a disease (Genetics Home Reference, 2015).

BRCA Genes. BRCA1 and BRCA2 stands for breast cancer susceptibility gene number 1 and gene number 2. These genes belong to a group of tumour suppressor genes. The primary function of these genes is to prevent cells from growing either too rapidly or in an uncontrolled fashion. When a parent passes down a copy of a mutated BRCA1 or BRCA2 gene to their offspring, the child carrying one of these hereditary mutations is at an increased lifetime risk for the development of breast and/or ovarian cancer (National Cancer Institute, 2013).

Mutation. In the field of genetics, the word "mutation" refers to a change in the sequence found in the genetic material known as DNA. DNA (deoxyribonucleic acid) is a molecule that acts as an information storage system in the body. A mutation in the sequencing/pattern of a gene can alter its function (Genetics Home Reference, 2015).

Penetrance. In genetics, complete penetrance means that all individuals who inherit a certain disease causing gene mutation will exhibit clinical symptoms. An incomplete penetrance means that clinical symptoms associated with a disease is not present in all individuals who inherit the genetic mutation that causes the disease (Genetics Home Reference, 2015). In breast cancer genetics, none of the known breast cancer susceptibility genes confer complete penetrance. Penetrance is currently estimated among known breast cancer susceptibility genes as high, moderate, and low (National Library of Medicine (US), 2015).

Relative Risk. Relative risk refers to an estimate that compares the risk among individuals who are exposed to something that may impact their health to those who are not exposed to something that could impact their health (Agency for Healthcare Research and Quality, n.d.). For example, drinking alcohol or smoking cigarettes could increase an individual's risk for a medical condition two or more times that of the individual who does not drink alcohol or smoke cigarettes.

Unaffected. In this research project the term unaffected is used to refer to individuals who do not have a personal history of breast and/or ovarian cancer.

Organization of the Thesis

In Chapter one, I discussed how I came to direct my attentions to the experiences of unaffected women who are considered at-risk for hereditary breast cancer and live in families where a known harmful BRCA1/2 gene mutation could not be identified. I also provided the purpose of the study and the research question that guided this inquiry and listed definitions for key terms used throughout the dissertation. In Chapter 2, I provided a review of the literature on aspects relevant to the proposed study population and rationale for the proposed research question. In Chapter 3, I provided: 1) rationale for applying Max van Mannen's hermeneutic phenomenological method; 2) a brief history of phenomenology; and 3) introduced van Manen's hermeneutic phenomenological method and discussed how I applied it. In Chapter 4, I shared the findings for this study. The format for writing direct quotes from participants in this study in chapters 4 and 5 are: italics, indentation for quotes greater than 24 words, single spacing, and no referencing. In Chapter 5, I reviewed unique insights that emerged from the current study, identified insights that are similar to relevant studies in the breast cancer literature, and discussed study limitations. In Chapter 6, I provided a conclusion and discussed implications for practice, policy, education, and future research.

CHAPTER 2 – LITERATURE REVIEW

The focus of this review was to explore what we know about how unaffected women (those without a personal history of breast and/or ovarian cancer), who live in BRCA1/2 mutation negative families experience living with risk for hereditary breast cancer (HBC). However, given the scarcity of literature on this population it was necessary to include relevant research on affected and unaffected women in order to give a broad overview of certain aspects pertaining to this topic and for comparison purposes. Additionally, where warranted, studies on women at-risk for hereditary breast and/or ovarian cancer (HBOC) were included. A broad electronic search using 11databases (Cinahl, Medline, Embase, PsycInfo, Cochrane Library, Sociological Abstracts, Social Services Abstracts, Social Sciences Citation Index, Anthropology Plus, Proquest Dissertations and Theses for North America, the United Kingdom and Ireland) was conducted with the following key words on their own or in combination with: genetics, risk, high, family, BRCA1, BRCA2, breast cancer, breast neoplasms, experience, uninformative negative, breast cancer screening, ovarian cancer screening, prophylactic mastectomy, prophylactic oophorectomy, and chemoprevention.

Given that a strong family history of breast and/or ovarian cancers signify a possible genetic basis for the development of breast and/or ovarian cancer, I begin with a review of some of the science behind BRCA genetic testing and risk models to outline what the results mean and how breast cancer risk is determined in the absence of a deleterious mutation. Next, I provide a discussion on the efficacy and psycho-social consequences of risk management options offered to women considered at-risk for HBC. I then discuss the female breast as object and lived. The breast as object is presented to show how cultural meanings and the medical objectification of the breast can disembody and overshadow a woman's personal narrative when faced with the

threat of a potentially fatal disease such as breast cancer. As lived, the breast is presented as a part of the body that is integral to the formation of a woman's self-identity through experiences of being-in-the-world (Young, 2005).

The final section of this review of the literature focuses on the psychological impact and experiences of living with the knowledge that a BRCA mutation has not been found in the family. At the end of this chapter, I provide closing remarks on the literature to support the following research question that guided this project: *How do unaffected women with at least a 20% lifetime risk for breast cancer experience living with risk when a BRCA1/2 genetic mutation has not been found in the family?*

BRCA Genetic Testing

In the 1990s, the discovery of a link between specific mutations in the breast cancer 1 (BRCA1) and the breast cancer 2 (BRCA2) susceptibility genes and high incidences of breast and ovarian cancer led to the availability of diagnostic and predictive genetic testing to identify these mutations and offer a more precise risk estimate for those identified as carriers (Miki et al., 1994; Wooster et al., 1995). Given that deleterious BRCA1/2 gene mutations are rare in the general population, with a cumulative frequency of about 1 in 800 for BRCA1 mutations and 1 in 500 for BRCA 2 mutations, testing for these mutations is not recommended for everyone. (Ghoussaini, Pharoah, & Easton, 2013; Antoniou, Cunningham, et al. 2008). Appendix A provides a comprehensive listing of Referral Criteria for Hereditary Cancer Syndromes from Alberta Health Services in Alberta, Canada.

Determination of an individual's lifetime risk for HBC and risk for carrying a deleterious BRCA1/2 mutation requires the construction of a family cancer history pedigree to examine patterns and age of onset on the maternal and paternal side. In conjunction with the evaluation of

a family cancer pedigree, some clinicians may use one or more genetic risk models to quantify the probability of carrying a BRCA mutation as well as a woman's projected lifetime risk for HBC. Given that a BRCA1/2 mutation was not identified in the families of the women in the present study, I reviewed relevant risk models used to estimate a woman's lifetime risk for HBC.

Genetic Risk Models – Benefits and Limitations

Jacobi, Bock, Siegerink, and van Asperen (2009) used several risk models to compare breast cancer risk estimates in healthy women living in untested or BRCA1/2 mutation negative families. The authors concluded that the BOADICIA and the IBIS models performed well for this population of women and recommend their use in current clinical practice. However, one of the criticisms of the BOADICEA risk model is that it is time intensive and difficult to use. To obtain an accurate risk assessment, family history information such as the year of a family member's birth or death is required - information that may be difficult for some relatives to obtain. The type of cancer can also skew the results. In the BOADICEA model, information on in-situ and non-epithelial cancers may lead to an overestimation of risk due to the absence of these forms of cancer in the population data. Additionally, in families with a strong ovarian cancer history and women identified as BRCA mutation negative, the BOADICEA model has been found to underestimate ovarian cancer risk (Weissman, 2013).

Although the IBIS model is comprehensive, widely used, and user-friendly, there are some drawbacks to this model as well. Quante et al. (2012) assessed the performance of the IBIS model in a large cohort of women (N = 1,857) of average and above-average risk for breast cancer. Risk calculation data used in this model includes: BRCA1/2 mutation status, extended family cancer histories, hormone replacement therapy use, height and weight to calculate body mass index, histories of atypical hyperplasia and hyperplasia, as well as in-situ lobular

carcinoma, current age, age at first live birth, and a woman's age at menopause. Although Quante et al. found that the IBIS performed well in calculating risk in groups of women at average or above-average risk, Antoniou and Easton (2006) questioned the accuracy of risk estimates for relations among relatives other than the mother-daughter relation given that the hypothetical data used in this model is based on mother-daughter pairs only (as cited in Weissman, 2013).

Thus, the preceding account of some of the benefits and limitations of the above-mentioned genetic risk models supports the recommendation made by Antoniou, Hardy, et al. (2008) to utilize these risk models as an adjunct - not in lieu of a healthcare professional's clinical judgment.

BRCA Gene Mutation Testing – What the Results Mean

Individuals who are considered at high risk for carrying a deleterious BRCA mutation are offered diagnostic or predictive genetic testing. As a diagnostic test, affected individuals considered at high risk (those with a personal history of breast/ovarian cancer and usually with a significant family history of breast/ovarian cancer) are usually the first persons to be offered testing. Individuals undergoing diagnostic BRCA genetic testing can expect to receive one of three results which include: a positive mutation, an unclassified variant, and an uninformative negative result. Unaffected blood relatives are usually only offered predictive genetic testing once a known harmful mutation has been found in an affected blood relative (National Cancer Institute, 2013).

A positive BRCA result means that a specific mutation that has been linked to high incidences of breast/ovarian cancer in other people has been identified in the blood sample of the individual being tested (National Cancer Institute, 2013). Chen and Parmigiani (2007) estimated

that by 70 years of age the average cumulative risk for breast and ovarian cancer was 57% (95% CI, 47% to 66%) and 40% (95% CI, 35% to 46%) in female BRCA1 mutation carriers; whereas female carriers of a BRCA2 mutation could expect an average cumulative risk of 49% (95% CI, 40% to 57%) for breast cancer and 18% (95% CI, 13% to 23%) for ovarian cancer, respectively (Schroeder & Conroy, 2015).

Once an individual is identified as a carrier of a deleterious BRCA1/2 gene mutation, their blood relatives may undergo predictive testing to find out if they carry the same mutation. In the case where the previously identified mutation is not found in a blood relative, this result is called a true negative. A true negative result implies that the individual's lifetime risk for breast and ovarian cancer is about the same as the general population. If a blood relative is identified as a carrier of the same harmful mutation found in an affected family member, it is hoped that the lifetime risk counselling for developing HBOC that these individuals receive will help them to make informed decisions when considering intensive surveillance measures, chemoprevention agents, and/or risk-reducing surgeries (National Cancer Institute, 2013).

An unclassified variant is considered ambiguous because the impact of the alteration in the BRCA1/2 gene sequence on an individual's risk for the development of HBOC is unknown (National Cancer Institute, 2013). Although the effects of many unclassified BRCA1/2 variants will be identified as being benign, some will be pathogenic. Between 2002 and 2012, the rate for unclassified variant results declined from 12.8% to 2.9% of all BRCA1/2 test results in the mutation databases of Myriad Genetic Laboratories in the United States (Eggington et al. 2012).

When a mutation is not detected in the blood sample of an affected family member, clinical judgment is used to assess whether the negative result may be considered uninformative. There are several reasons for a negative result. Although the accuracy of current technology to

detect deleterious BRCA1/2 mutations is about 98%, it is possible that either the result is a false negative or an undiscovered gene mutation is present but current technology is unable to detect it (National Cancer Institute, 2013). Additionally, it is also possible that bad luck has a role to play in the development of breast cancer. For example, if a thirty year old woman diagnosed with a triple negative breast cancer undergoes genetic testing and receives a negative genetic test result, an assessment of her family's cancer history and the use of a risk model to calculate risk may be employed to determine whether a predisposition for breast cancer is due to a mutation in one or a group of genes or bad luck. In this example, the young woman's negative result would be considered uninformative as long as there is a strong enough family breast and/or ovarian cancer history to support a suspicion of there being an inheritable genetic basis for these cancers (personal communication, B. Krause).

Other Breast Cancer Susceptibility Genes

Although women who meet specific criteria for HBOC syndrome may be offered genetic testing to detect certain BRCA1/2 gene mutations, many other breast cancer susceptibility genes of variable penetrance (refers to the chance of developing a disease in individuals who test positive for a deleterious mutation) are described in the literature (deJong et al. 2002; National Cancer Institute, 2013). For example, the BRCA1/2, CDH1, STK11, PTEN, and TP53 genes are referred to in the literature as having high penetrance whereas the ATM, BRIP1, CHEK2, and PALB2 are referred to as moderate penetrance genes (Stratton & Rahman, 2014). I now briefly discuss six known genes associated with hereditary breast cancer - ATM, CHEK2, TP53, PTEN, CDH1, and PALB2 – to illustrate differing penetrance rates, the rarity of these mutations, and to identify other comorbidities/risks for other diseases associated with certain mutations (Thompson & Easton, 2004; Renwick, et al. 2006; Antoniou, et al. 2014;). For example,

although deleterious mutations in moderate penetrance genes such as the CHEK2 gene are reported to occur in about 5% of familial breast cancers, an individual's risk is likely to be less than 20% for breast cancer (Meijers-Heijboer et al. 2002; Stratton & Rahman, 2008).

In another moderate penetrance gene known as ATM, Renwick et al. (2006) estimated a relative risk of 2.37% (95% CI, 1.51 to 3.78) for breast cancer in carriers of a subset of ATM gene mutations that cause a rare disorder known as ataxia telangiectasia. Mutations in other breast cancer susceptibility genes such as the TP53 and PTEN are considered quite rare – accounting for less than 1% of familial breast cancers (Easton, 1999; Rapakko et al. 2001; Fitzgerald et al. 1998). More recently, Antoniou et al. (2014) estimated the lifetime risk for breast cancer in families where an affected individual tested negative for a deleterious BRCA1/2 gene mutation and tested positive for a loss of function mutation in the PALB2 gene. Data was collected from 154 families. In this study, by 70 years of age, the authors estimated that the absolute breast cancer risk for female carriers of a PALB2 mutation ranged from 33% (95% CI, 25 to 44) for carriers with no family history of breast cancer to 58% (95% CI, 50 to 66) for female carriers with a strong family history for breast cancer.

Lastly, female carriers of a mutation in the highly penetrant CDH1 gene face not only a high lifetime risk for lobular breast cancer (updated to approximately 60%), they are also given a cumulative lifetime risk estimate of 83% for the development of hereditary diffuse gastric cancer (Kluijt, et al. 2012; Pharoah, Guilford, Caldos, et al. 2001). Asymptomatic women identified as carriers of this mutation may be asked to consider surveillance and risk-reducing options for hereditary breast cancer as well as a prophylactic total gastrectomy (PTG). Although a PTG is an effective risk-reducing strategy, residual symptoms such as: diarrhea, reflux, body image issues, discomfort when eating, and fatigue may persist following surgery (Worster, et al. 2014).

Recent discoveries of many other gene variants associated with breast cancer risk point to future possibilities in genetic testing where the combined effects of multiple variants may be used to calculate a woman's personal risk for breast cancer. The development of a personalized risk stratification tool, including such additive genetic factors, to assess for breast cancer risk in women who are carriers of a BRCA mutation or those who receive an uninformative negative or unclassified variant result is one of many aims currently being worked on by researchers around the world who are involved in the Collaborative Oncological Gene-environment study (Burton et al. 2013; Michailidou et al. 2013). However, until these tools are ready for wide-spread clinical use, in Alberta, women who are identified as carriers of a harmful BRCA1/2 genetic mutation, untested women who have a first degree relative identified as a BRCA1/2 gene mutation carrier, or women who have been identified by a geneticist or a high risk clinic as having a projected lifetime risk for breast cancer of at least 20-25% are considered to be at high risk for HBC or HBOC (depending on the family history pedigree) (Alberta Health Services, 2011).

Efficacy of Risk Reducing and Surveillance Management Options

Although Metcalfe, et al. (2009) estimated a lifetime risk for breast cancer of approximately 40% in a large population of unaffected women (N = 1,492) living in BRCA mutation negative families, a significant increase in risk for ovarian cancer in these families and the BRCA mutation negative families studied by Kauff et al. (2005) was not found. Therefore, the recommendation from Metcalfe et al. was to focus on breast cancer management strategies. Currently, determination of the efficacy of surveillance and risk-reducing management options for women living in BRCA mutation negative families is under investigation (Kotsopoulos, et al. 2014). Given that more is known about the efficacy of breast and/or ovarian cancer management

strategies among BRCA1/2 mutation carriers, I now discuss changes in survival probabilities based on risk management options for this population.

Kurian, Sigal, and Plevritis, (2010) developed a computer simulation model to create histories for a large simulated cohort of women (N=1,000,000) with a BRCA1/2 mutation and used empirical data from the literature to compare the efficacy of breast cancer screening and risk-reducing surgeries. The authors estimated that women who do not undergo any interventions can expect a survival probability at 70 years of age of 53% for those carrying a BRCA1 mutation and 71% for those carrying a BRCA2 mutation. Survival probabilities increased to 79% in BRCA1 mutation carriers and 83% in BRCA2 mutation carriers when a mastectomy was performed at 25 years of age and an oophorectomy was carried out at 40 years of age. The increase in survival rates due to prophylactic risk-reducing surgeries provides women with BRCA1/2 mutations with survival rates closer to that of the general population (84%). However, it is important to note that although the age of 25 for a prophylactic mastectomy combined with an oophorectomy at 40 years of age yielded the best possible survival gain – waiting till the age of 40 to have a mastectomy only reduced the overall gain by between 1 and 2% (Kurian, Sigal, & Plevritis).

Additionally, an interesting finding in their analysis was that when a woman who is BRCA1/2 mutation positive has a prophylactic oophorectomy at 40 years of age and participates in breast cancer screening in place of a prophylactic mastectomy, the loss in survival is between 2% and 3%. Thus, the authors concluded that the results from their evaluation of survival gains in risk-reducing surgeries and breast cancer screening practices could be useful for women as they decide on which path to take to monitor their breast health and/or reduce their lifetime risk for HBOC (Kurian, Sigal, & Plevritis, 2010).

MRI, and Mammography Screening for Breast Cancer

Given that mammography screening in any population is the only test associated with a reduced mortality rate, the consensus is to offer women at high risk for breast cancer screening tests such as magnetic resonance imaging (MRI) and ultra-sound (U/S) in addition to mammography screening. The specificity (meaning the closer a rate approaches 100% the more certain we are that a negative result is a true negative) and sensitivity (meaning the closer a rate approaches 100% the more certain we are that a positive result is a true positive) rates are important factors that are taken into account when recommending a screening test alone and/or in conjunction with others.

Warner, Messersmith, Causer, et al. (2007) conducted a systematic review of 12 prospective observational studies that offered women, at high risk for breast cancer, MRI and mammography screening on an annual basis. In this analysis, the combined sensitivity rate for mammography screening alone was much lower than MRI screening (36.8%, 95% CI 29.6 – 44.5% versus 80.1%, 95% CI 73.3 – 85.8%). Interestingly, the combined specificity rate for mammography screening alone was higher than the MRI (97.5%, 95% CI 97.1 – 97.8% versus 93.0%, 95% CI 92.5 – 93.6%). However, when the sensitivity and specificity rates for mammography and MRI screening tests were combined, the increase in the sensitivity rate (87.4%) and the sustained high specificity rate (94.2%) provided evidence-based rationale for adding the MRI to the mammography screening schedule (Alberta Health Services, 2011; Warner, et al).

Most experts agree that high risk women should be offered an MRI and mammogram on an annual basis. In doing so, the tests are staggered so that the tests are 6 months apart. However, one of the shortfalls in offering annual MRI screening is the increased risk for women to be

recalled to investigate a false-positive result. Lehman (2006) reviewed the results of 8 clinical trials exploring the sensitivity and specificity of MRI screening in high risk women. Although the clinical trials revealed a recall rate for additional imaging that ranged from 8 to 17%, overall, breast cancer was detected by MRI in 3% (N=144) of the combined population (N=4,271) (Lehman). Additionally, it is important to note that some high risk women will not be able to undergo or tolerate MRI screening due to claustrophobia and/or the presence of a pacemaker, magnetic clips, magnetic/mechanical/electronic implants, etc. In this case or in the case where an MRI is not available where the individual resides, an ultra-sound may be offered in place of the MRI. Overall, experts recommend annual mammogram screening in conjunction with MRI and in certain cases an ultrasound and bi-annual clinical breast exams to monitor the breast health of women at high risk for breast cancer (Alberta Health Services, 2011).

Psychological Impact of Breast Cancer Screening

Although regular participation in breast cancer screening programs has been found to alleviate feelings of anxiousness and worry in some women at high risk for HBOC, stress over the possibility of learning of a suspicious growth after undergoing MRI screening and the time spent waiting for the result can transport a woman into a space where life is placed in a holding pattern as the threat of cancer comes to the foreground (Parsons, Beale, Bennett, Jones, & Lycett, 2000; Underhill, Lally, Kiviniemi, Murekeyisoni, & Dickerson, 2012).

Researchers have examined factors and predictors for increases in cancer worry and changes in quality of life around the time of mammography screening in women at moderate to high risk for HBOC. Brain et al. (2008) identified pre-screening cancer worry levels, high perception of breast cancer risk, and low perception of one's capacity to cope emotionally as important predictors for later cancer worry among a large cohort (N=1286) of younger women

(below 50 years of age) in a family history breast cancer screening program who underwent mammography screening and were followed for 6 months after receiving results. Similarly, Henderson et al. (2008) identified high perception of cancer risk as well as low levels of optimism, avoidant coping behaviour, and a high valuation of one's family cancer history as threatening, as factors associated with breast cancer-related distress within a large cohort of young women (N = 2321; below 50 years of age) who underwent mammography screening in a family history breast cancer screening program.

Tyndel et al. (2007) examined the positive and negative psychological impact of mammographic screening among 1,286 women (below 50 years of age) who had a family history of breast cancer and underwent mammography screening. In this cohort, all of the women eventually received all-clear results. For the women who immediately received an all-clear result, their cancer worry levels decreased immediately, whereas cancer worry levels among those women who were recalled for further investigation of suspicious findings did not decrease immediately but were much lower at the 6 month interval following disclosure of final results. Interestingly, the women (N = 112) who were recalled reported significantly higher positive psychological consequences related to screening than the group of women who received an immediate all-clear result. The authors concluded that the positive views on mammography screening held by women who were recalled for additional testing may have helped them to see the distress they experienced as an acceptable part of screening (Tyndel et al.).

The psychological impact of MRI screening was recently examined by O'Neill et al. (2009) in a group of women (N = 113) at high risk for HBOC. In total, 189 MRI scans were conducted in this group of women. In this study, breast cancer was diagnosed in 2 out of 21 (9.5%) women who underwent additional testing for an abnormal result and the false positive

rate was 10% (19/187). Overall, although increases in psychological disturbances among the women who were recalled for a second MRI was minor, intrusive and avoidance cancer- related thoughts in women with a BRCA1/2 mutation increased significantly at the second MRI.

The impact of high risk breast cancer screening programs on a woman's health related quality of life is another aspect of the screening experience that has been investigated. Rijnsburger et al. (2004) assessed the short term impact of mammography and MRI screening on health related quality of life in a large cohort (N=519) of women at high risk for breast cancer. Significant discomfort was reported by 30% of the women who underwent mammography screening, while some discomfort was reported by 69.2% of those who underwent mammography and 45.3% of those who underwent MRI screening. Additionally, more than a third (37%) of the women who underwent MRI screening reported feeling anxious about the procedure. Despite reports of discomfort and anxiousness, these procedures did not have a detrimental impact on general health related quality of life and general distress levels in these women. Possible reasons suggested by the authors include: 1) the length of time these women have participated in a screening program; and 2) the belief that they are doing as much as is possible to cope with their breast cancer risk.

Ovarian Cancer Screening

Given that earlier studies by Metcalfe et al. (2009) and Kauff et al. (2005) did not identify a significant increase in risk for ovarian cancer among women living in BRCA negative families, it is more common to focus on breast cancer management options. However, as was found in the present study, some BRCA mutation negative families (although the minority) can have an ovarian cancer history that warrants counsel on certain ovarian cancer management strategies. The recommendation for women at high risk for HBOC to undergo annual trans-vaginal

ultrasound (TVU) and serum CA125 testing to detect ovarian cancer remains controversial due to their low positive predictive value and low efficacy of detecting cancers at an early stage. A positive predictive value (PPV) is expressed as a percentage value that refers to the proportion of people - with a positive screening result - who truly have the disease. Several researchers have found insufficient evidence to support annual TVU and serum CA-125 testing. For example, Van Nagell et al. (2007) identified a low PPV of 14% in a large population of average-risk women who underwent annual TVU screening between 1987 and 2005. An even lower PPV of 1.5% was identified by Woodword et al. (2007) when they assessed the records of 341 asymptomatic women with low to high cancer-risk estimates, who underwent annual serum CA-125 and TVU between 1996 and 2005. In this study, out of the 30 women who underwent exploratory surgery after receiving an abnormal result, only 2 were diagnosed with ovarian cancer (Woodword et al.). Thus, ovarian cancer screening may result in unnecessary anxiety and exploratory surgeries due to its low PPV.

In addition to the poor PPV identified in CA-125 blood tests and TVU, the ability of these screening methods to detect ovarian cancer at an early stage is weak. Hermsen et al. (2007) evaluated the efficacy of annual ovarian cancer screening that combined serum CA-125 and TVU in BRCA1/2 mutation carriers to detect early stage cancers and found that 80% (8/10) of ovarian cancer diagnoses were identified at stage III/IV in a sample population of 888 BRCA mutation positive women. Gaarenstroom et al. (2006) also found that most of the ovarian cancers (N=8) identified in their population of high risk women who underwent serum CA-125 and TVU (N= 269) were detected at an advanced stage.

Prophylactic Mastectomy and Risk-Reducing Salpingo Oophorectomy

By far, the highest reduction in lifetime breast cancer risk – of up to 95% - has been shown in women who undergo both a prophylactic bilateral mastectomy (PBM) and a risk-reducing salpingo oophorectomy (RRSO). Women who prefer to undergo a RRSO on its own can benefit from a substantially reduced risk for ovarian cancer. Additionally, a RRSO can substantially reduce a premenopausal woman's risk for breast cancer. On its own, a prophylactic bilateral (PBM) mastectomy can reduce a woman's lifetime risk for breast cancer by up to 90% (Rebbeck et al. 2004; Hartmann et al. 2001; Meijers-Heijboer et al. 2001; Kauff et al. 2002; Rebbeck et al. 2002).

Kotsopoulos, et al. (2014) are currently conducting a prospective study to estimate risk reduction rates with prophylactic surgery and certain chemoprevention drugs along with other factors associated with risk for breast cancer in a large population (N = 1000) of unaffected Canadian women living in BRCA mutation negative families with a strong familial history for breast cancer. One of the aims of their study is to determine appropriate breast cancer prevention and screening practices for this population of women. In light of the scarcity of research focused on the experiences of unaffected women who live in BRCA mutation negative families and undergo a PBM, I now provide a brief overview of some of the positive and negative outcomes associated with a prophylactic mastectomy from studies that combined the responses of unaffected and affected women at high risk for breast cancer.

A PBM is a surgery that entails the removal of both healthy breasts. There are different ways to go about the removal of breast tissue. Women with no personal history for breast cancer can opt for a skin-sparing PBM or nipple-sparing PBM to preserve the nipple and achieve a more natural looking breast after reconstruction. Brandberg et al. (2008) assessed for changes in a

woman's sexuality, body image, general anxiety, and depressive symptoms following a PBM in women (N = 90) at high risk for breast cancer. Although avoidance and intrusive thoughts related to cancer were not measured in this study, the findings showed an improvement in the women's general anxiety levels, whereas no differences in depressive symptoms were identified over time. However, some of the women reported that the surgery had a negative impact on their body image and sexuality (Brandberg et al.).

In an earlier study by Bresser et al. (2007), changes in distress before and up to 12 months following a prophylactic mastectomy and/or a risk-reducing salpingo-oophorectomy were examined in a group of affected and unaffected women (N=78) at increased risk for HBOC. Separate analyses were done for each prophylactic surgery. In the sample of affected and unaffected women who underwent a prophylactic mastectomy (N=52), 36 were identified as BRCA1/2 mutation carriers and 16 were identified as being at an increased risk for HBOC. The mean age for the women in the prophylactic mastectomy group was 40 years (25 – 65). Responses from the Hospital Anxiety and Depression Scale (HADS) and the Impact of Events Scale (IES) questionnaires were analyzed to detect changes in general anxiety and cancer-related distress. Overall, significant decreases were observed in this group of women in relation to anxiety as well as avoidance and intrusive thoughts related to cancer (Bresser, et al.).

Whereas several studies have reported on the impact of a prophylactic mastectomy on its own, Bresser, et al. (2006) reported on the impact of a prophylactic bilateral mastectomy (PBM) or contralateral prophylactic mastectomy (removal of a healthy breast along with the cancerous breast) as well as breast reconstruction surgery. In their sample of 114 women, 77 were unaffected BRCA1/2 mutation carriers, 22 had a personal history for breast cancer, and 14 unaffected women were identified as having a 50% risk. Since the responses from affected and

unaffected women did not differ significantly, the results were combined. In this sample, the mean age was 44 years (25-65) and the median follow-up time following surgery was 3 years (0 to 8). An analysis of the responses on the questionnaire indicated that only 60% of the women were satisfied with the outcomes from the breast reconstruction surgery. Some of the reasons for being dissatisfied with the results of these surgeries included: not feeling like their breasts were their own, not feeling sufficiently informed and changes in relation to how they felt about their femininity. Sexual relations were reported as being negatively impacted by the surgeries in almost half (44%) of the women (N=90) who answered questions about their sexuality (Bresser, et al.).

In summary, although the findings in the above studies show decreases in general anxiety and avoidance/intrusive thoughts related to cancer in many women who underwent a prophylactic mastectomy, for some women, this surgery can have a negative impact on body image and sexual relationships. It is interesting to consider that for some of the women in the Bresser, et al. (2006) study, a lack of information and discordant expectations were strongly correlated with negative outcomes related to their sexual relationships. Even though there is widespread support among clinicians to integrate psychological counseling before and after a PBM, this type of support is not routine in all HBOC centres (Patenaude, et al. 2008; Tan, et al. 2009). Hence it could be that the routine integration of psychological support for high risk women contemplating a PBM will help to prevent negative outcomes in relation to a woman's sexuality and body image and/or to identify women who are not psychologically ready for this type of surgery.

Women at an elevated risk for HBOC who are contemplating a RRSO are usually advised to undergo the procedure either at/or after 35 years of age or once childbearing is complete

(Armstrong, Schwartz, Randall, Rubin, & Weber et al. 2004). Rationale for high risk women to undergo a RRSO around 35 years of age is due to the rise in ovarian cancer risk before age 40 (King, Marks, & Mandell, 2003). Although this procedure greatly reduces a woman's risk for ovarian cancer (risk cannot be zero due to the possibility of developing a peritoneal cancer), the removal of the ovaries – especially in premenopausal women – can bring on several adverse effects associated with an immediate surgically induced menopause. Menopausal symptoms that may be experienced include: hot flushes, sleep disturbances, urogenital atrophy, mood swings, depression, and sexual dysfunction. (Bachmann, 1999; Shifren, Nahum, & Mazer, 1998; Elit, Esplen, Butler, & Narod, 2001). All of these symptoms can have an effect on a woman's quality of life. Depending on the severity of symptoms that manifest following a RRSO, recommendations for the short-term use of certain hormone replacement therapies may be considered to alleviate symptoms up to the point where a woman would naturally experience menopause (Armstrong et al. 2004). Pre-menopausal women undergoing a prophylactic oophorectomy are also at an increased risk for long-term negative health outcomes such as: cardiovascular disease, bone fractures and osteoporosis, cognitive impairment, and parkinsonism (Shuster, Gostout, Grossardt, & Rocca, 2008).

Chemoprevention

Recently updated ASCO guidelines on pharmacologic interventions used to reduce invasive breast cancer risk in women with an elevated risk continue to support the use of tamoxifen and raloxifene, and add a recommendation for the use of exemestane as an alternative (Visanathan et al. 2013). Tamoxifen can be offered to pre- and post-menopausal women whereas raloxifene and exemestane are recommended for post-menopausal women. Tamoxifen and raloxifene are selective estrogen reduction modulators (SERMs). SERMs work by traveling

to cells with estrogen receptors and competing with estrogen to attach to those receptors. Estrogens are agonists that can stimulate the growth of cancer cells that are positive for estrogen receptors. The action of SERMs depends on the type of cells to which they bind. For example, when attaching to estrogen receptors found in bone, liver, and cardiovascular tissue, these chemicals act as agonists – triggering a response by that cell. In breast and brain tissue, SERMs act as antagonists to inhibit a biological response. Thus, SERMs can provide beneficial effects to bone and cardiovascular health while preventing the development of estrogen positive breast cancers (Lewis & Jordan, 2005).

Several randomized controlled clinical trials have shown favourable reductions in invasive breast cancer risk among pre- and postmenopausal women who took tamoxifen and postmenopausal women who took raloxifene over a 5 year period (Fisher et al. 1998; Cummings et al. 1999; Barrett-Conner et al. 2006; Vogel et al. 2010). However, an update on the National Surgical Adjuvant Breast and Bowel Project Study of tamoxifen and raloxifene (STAR) reported higher risk-reduction benefits with long-term tamoxifen use compared to raloxifene. Following a median follow-up interval of 81 months, raloxifene retained about 76% of the effectiveness of tamoxifen. This means that raloxifene reduced invasive breast cancer risk by about 38% (Vogel, et al. 2010).

As an alternative to tamoxifen and raloxifene, the ASCO guidelines now recommend the use of an aromatase inhibitor, known as exemestane, as an invasive breast cancer risk reduction option for postmenopausal women at elevated risk for breast cancer – specifically breast cancers that are estrogen receptor positive. Tamoxifen and raloxifene are considered primary options for women to consider over exemestane due to the strength of the evidence available (Visanathan et al. 2013). However, there is a wide range of possible side effects to consider when offering

women endocrine therapies such as tamoxifen, raloxifene, and exemestane. For example, women who are offered tamoxifen may experience side effects such as: hot flashes, fatigue, vaginal dryness, as well as an increased risk for cataracts, endometrial cancer and blood clots (National Cancer Institute, 2013; Rosenberg, Stanton, Petrie, & Partridge, 2015; Vogel et al., 2010). Although post-menopausal women receiving raloxifene experience fewer endometrial cancers when compared to those receiving tamoxifen, raloxifene users may experience hot flashes, leg cramps, peripheral edema, and an increased risk for blood clots (Vogel, et al. 2010; Martino, et al. 2004). Whereas post-menopausal women who are taking exemestane may experience side effects such as: hot flashes, joint and muscle pain, fatigue, vaginal dryness, and a decrease in bone mineral density during treatment (Goss et al. 2011; Coleman et al.2007).

The Female Breast as Object and Lived

Edvard Munch, *Ashes*, 1895

The painting above by Edvard Munch entitled – Ashes – illuminates a feeling of despair as the woman looks forward with much of her chest pushed forward and exposed to an uncertain

future while the man in the foreground shields himself from what may lie ahead. The threat of hereditary breast cancer may alter a woman's perception of her breasts – leading her to contemplate her own mortality and the meaning she attaches to the breast as she looks to an uncertain future. Throughout recorded history, the breast has been inscribed with cultural meanings that signify societal expectations for a woman's comportment and place in society. The writings of Foucault about the body suggest that the body is viewed as a surface to inscribe meanings derived from historical cultural discourse and regimes of power. It was Foucault's belief that history uses the body as a canvas to be deconstructed and transformed in order to change cultural beliefs (Butler & Welton, 1999).

As life-giving, in the fourteenth century, the breast was represented as a sacred vessel in the first paintings of the Virgin Mary as she nursed the baby Jesus. In contrast, the breast as the giver of life has long been known as a space that could end one's life. Unlike other cancers that are not visible to the eye, breast cancer has endured a rich and long history due to its highly visible and palpable nature. Although Hippocrates (460-377 B.C.E.) penned the most enduring description of a cancerous tumour of the breast, the ancient Egyptians described diseases located on the breast on papyrus about a thousand years prior to the emergence of European medicine in classical Greece. The breast is also presented as an erotic symbol of a woman's sexuality – an intimate part of the body that is called to attention through the gaze and caress of the other (Yalom, 1997; Schroeder & Conroy, 2015).

Throughout history, as the breast is exposed or concealed, denigrated or praised - one of the most basic and important questions posed by the historian, Marilyn Yalom (1997), is: "Who owns the breast?" (p. 3). This question urges us to consider whether the breast belongs to the infant needing nourishment from it, the partner who seeks sexual pleasure from it, the artist

rendering his/her perception of the ideal female form, the physician who monitors its health, or the clothing, film, and advertising industries that project upon us the ideal bosom. Thus, the question concerning to whom the breast belongs and the myriad of historical/cultural meanings attached to it reveals the breast as an object that is in some ways detached from the owner and therefore void of personal meaning.

As lived, Young (2005) suggests the female chest is phenomenologically "at the center of a person's being-in-the-world and the way she presents herself in the world" (p. 94). As part of a woman's sense of self, the breast symbolizes experiences of being-in-the-world that are tied to the forming of self-identity. During adolescence the protruding breast signifies an inscription upon the body that conveys a transition from childhood to womanhood as well as a sign of her sexuality that can be judged by the objectifying male gaze. As a visible sign of a woman's femininity, the ideal breast in Western society is lifted high up on the chest, large, and firm. As territory, Young suggests that Western society views the female breast as belonging not only to the woman but to her lover and infant. And, as object, the breast can be "handled, manipulated, constructed, built up and broken down" to conform to the cultural values and meanings placed upon it (Young, p. 78).

Western society's ideal form of the breast may conflict with the threat of an elevated hereditary risk for breast cancer as a woman's risk takes hold to imbue new meanings. The marking that an elevated risk for breast cancer brings to a woman's sense of self may open the door to further objectification of the breast through various medical management options that are meant to reduce risk and/or hopefully detect breast cancer in the early stages. Although current knowledge and technology that is available to prevent, detect, and in many cases cure breast cancer is quite remarkable, it is important not to lose sight of the person living with the risk for

this disease. Heidegger (1977) reminds us to think about modern technology as a way of revealing and challenging that which appears to us prior to its transformation. In this sense, once one's risk status is established and surveillance of the breast begins, there is no turning back to the way we once perceived this integral part of the body/self. For a moment, the breast is somehow separated from the self as an object to investigate for the presence of cancer cells.

Although the objectification of the breast is necessary to detect and/or remove cancerous tumours, the embodied experience of the individual must not be forgotten. Merleau-Ponty (1962) believed that the body as a medium through which we experience and make sense of the world, is not to be perceived as an object for it is through our bodies that we may first identify objects or sense emotions such as anger emanating from the body of the other. However, as we move about in the world as embodied beings, the body in its fluid and unproblematic form is for the most part absent from our view. Hence, it is through the break-down of the body that we pause to reflect on a diseased part of the body that reveals itself as alien (Leder, 1990). As Leder writes, we become acutely aware of the body as alien when we experience a life-threatening illness. The woman who is diagnosed with breast cancer is thrown into an unfamiliar and unsettling space – a space where the threat to one's mortality may alter her sense of temporality and faith in her body.

However, the presencing of the body as alien need not be relegated only to those who personally experience a diagnosis of a life-threatening disease. Previous research has shown that for some unaffected women living with a harmful BRCA1/2 gene mutation, an awareness of their high HBC risk resulted in feelings of mistrust and anxiousness toward their breasts, changed their self-identity, and altered the ways in which time and relations with others were experienced (Hamilton, Williams, Skirton & Bowers, 2009; Crump, Fitzgerald, & Legge, 2010; Werner-Lin, 2008; Hamilton & Hurley, 2010; Underhill et al. 2012; Schroeder & Conroy, 2015).

In this sense, one might refer to the term "risk" as an alien presencing for it provokes women who are carriers of a BRCA mutation to experience and understand the self and world in a different way. But, whether or not risk is experienced as alien is not well understood in unaffected women who live in high risk families where a genetic mutation in a known breast cancer susceptibility gene cannot be found. Research to-date on this population of women provides quantitative data that measures the impact of genetic testing in the family on participation rates for breast cancer surveillance programs, psychological distress, and perceptions of cancer risk (Geirdal et al. 2005; Vos et al. 2011). Although this information is valuable, my concern is that if we rely too heavily on research methodologies in the health sciences that isolate and measure aspects of a woman's experience with risk for breast cancer, the restrictive lens through which we look will simply explain behaviour and miss out on a contextual understanding of human experience (Merleau-Ponty, 1964). Perhaps, as Bamforth (2003) suggests, the devaluing of subjective meaning in breast cancer research may be a consequence of the technological age of medicine wherein the body has been taken out of the library to become the "library in the body" (p. xxiv). In other words, the body may be viewed as an impersonal space where physiological processes become the focus and the individual experience of risk becomes irrelevant.

According to Gadow (1994), the language within the medical narrative presents the woman's body as pure object to be reduced to its components, removed or replaced in order to re-establish its function. The objectification of illness in contemporary medicine is referred to by Foucault (1973) as the medical gaze that centers on what is immediately visible and leaves uncovered that which falls outside of the hegemonic dialogue to be internalized by the patient. In this sense, medicine's hegemonic worldview effectively eliminates any value in the subjective

experience. Moreover, Gadow (1994) asserts that the use of theories to generalize and construct meaning within healthcare denies "women's access to their experience, access to meanings that establish the woman at the center of her own health" (p. 295). Therefore, to understand breast cancer risk from an unaffected woman's unique point of view, it is imperative that we engage in qualitative approaches to understand how they interpret risk and how risk plays out in their lives. Questions asked through a qualitative lens can only complement the medical narrative as we enhance our understandings of possible ways of experiencing breast cancer risk.

Over the past decade, a growing interest in the experiences of living with risk among women at high risk for HBOC has resulted in the capture of rich narratives in the nursing literature that place the woman at the center of her experience. Although one of the aims of this chapter was to review what we know about the experiences of unaffected women living with risk for HBC in the absence of a known BRCA1/2 genetic mutation, given that the literature on this population is thin, I include in the following section an overview of the psychological impact and experiences of both affected and unaffected women to show possible ways in which individuals may live with risk for HBC in the absence of a genetic explanation.

Living with an Awareness of Risk for HBC in the Absence of a BRCA1/2 Gene Mutation

The etymology of the word "risk" is questionable. On the one hand, its meaning can be traced back to the Latin word "resecare" – meaning "to cut off short or abruptly", while on the other hand - it can be connected to the Arab word "rizq", which is defined as good fortune or riches. As a maritime term, the Spanish word "risco" refers to the dangers of sailing too closely to a rock (Skeat, 1888, p. 512). The term "risk" is presented by Wilkinson (2001) as a paradox, in that "…knowledge of risk can be used to both unsettle and reassure those seeking to plan for the future…" (p. 90). In other words, when the term risk is used to refer to an outcome that is

unknowable, this knowledge may be internalized as a threat to one's well-being. On the other hand, if risk is used to signify an element of certainty, knowledge gained from predictions for diseases such as breast or ovarian cancer may offer women a sense of how likely it is that they may develop cancer in their lifetime.

The experience of living with the uncertainty associated with risk is recognized in the nursing literature as an important element connected with illness that nurses need to be aware of in order to help guide patients through the development and/or threat of disease (Corbeil, Laizner, Hunter, & Hutchison, 2009). The phenomenon of uncertainty has been defined by qualitative nursing researchers within the context of illness. For example, Hilton's (1988) work on the phenomenon of uncertainty among women experiencing breast cancer arrived at a definition that presents uncertainty as a "state that lies on a continuum and changes over time, is appraised in varying ways, and is accompanied by various emotions" (p. 220).

In recent years, how women considered high risk for HBOC cope with uncertainty in their daily lives and the meanings they attach to risk has been a topic of growing interest in the cancer nursing literature. In a study by Underhill and Dickerson (2011), where most of the women (seven out of nine) were identified as carriers of a BRCA1/2 mutation, their family cancer story was identified as the impetus for a growing awareness of their heightened risk for breast cancer. For these women, although they did not expect to be diagnosed with cancer around the time of a screening appointment, their worries were attached to the what-ifs each time they underwent a screening procedure (Underhill & Dickerson).

As was mentioned earlier in this literature review, women considered at high risk for HBOC may be offered screening options such as annual mammograms, ultrasounds, and MRIs to detect abnormal growths. The anticipation of a screening test and the waiting period women

experience between the test itself and disclosure of the result can be profoundly unsettling and filled with anxiety – placing life as these women know it on hold (Underhill et al., 2012). Another interesting element associated with living with uncertainty among women at high risk for HBOC is how ongoing medical vigilance and self-awareness of a heightened risk can make some women feel as if they are ill when they are actually healthy (Underhill & Dickerson, 2011). Labeling oneself as being ill in the absence of a diagnosis is a subject of ethical debate in predictive medicine. In nursing, we must ask ourselves is a woman at high risk for HBOC to be perceived and treated as "ill, healthy, asymptomatic but ill, or as an "unpatient" – since he/she may develop symptomatic disease in the future?" (Di Pietro, Giuli, & Spagnolo, 2004, p. i67; Schroeder & Conroy, 2015). How these labels impact a woman's sense of self and future possibilities are other questions we must ask ourselves.

At present, the nursing and psychological literature on the experience of living with uncertainty in predictive breast cancer medicine has focused primarily on the experiences of women living with a known deleterious BRCA genetic mutation. For these women, several researchers have uncovered a paradoxical world enmeshed with ongoing varying degrees of anxiety and hope as women use this risk information to make informed life decisions to reduce risk and/or detect cancer. Making these informed choices may empower and provide some women with a sense of being more in control of their risk (Radner, 2011; Dagan & Goldblatt, 2009; Hamilton & Hurley, 2010; Crump, Fitzgerald & Legge, 2010; Proulx et al. 2009). But, what happens to a woman's perception of breast cancer risk when a genetic explanation cannot be found - as in the case of a woman who receives an uninformative negative BRCA1/2 genetic test result?

Recall that a negative BRCA genetic test result is considered uninformative when a strong family cancer history suggests that there is likely a genetic explanation for the number or clusters of breast/ovarian cancers in the family. Although the chances of receiving a false negative result are low, it is possible that our current technology failed to detect a known mutation. It is also possible that a harmful mutation does exist but is yet to be discovered (National Cancer Institute, 2013). When a mutation is not found, one of the concerns is that a woman may change her breast cancer screening habits or decline an offer for risk-reducing surgeries if she falsely reassures herself that her lifetime risk has changed from high to low.

The false reassurance hypothesis among affected women who receive an uninformative negative result has been examined by researchers in the Netherlands, France, and Quebec. In three of the studies, up to 15% in two female Netherland populations and 30% in a French female population who received an uninformative result believed their chances of carrying a harmful mutation to be unlikely (van Dijk, Otten, Tollenaar, van Asperen & Tibben, 2008; van Dijk et al., 2005; Cypowyj et al., 2009). In the fourth study, Dorval et al. (2005) examined changes in indicators of reassurance that included: cancer-worry, risk perception, impact on quality of life, as well as pain and relief in a large Quebec female cohort (N = 255) who received an uninformative negative result. Women receiving uninformative negative results reported higher perceptions of cancer risk and cancer worries, felt less relief when learning of their result, and perceived a greater negative impact on quality of life when compared to the women identified as non-carriers (n=140) (Dorval et al.). Thus, the preceding studies not only refute the notion that an uninformative result will provide women with a false sense that their personal risk for HBC will be greatly reduced, but point to the potential for negative psychological effects.

The Psychological Impact of Learning of an Uninformative Negative Result in the Family

Only two reports were found specifically looking at changes in psychological distress levels among unaffected women who are not eligible for BRCA genetic testing due to the absence of a mutation in the family. Meiser et al. (2002) compared anxiety and depression levels between three groups of unaffected women twelve months post notification of BRCA genetic test results. The groups consisted of: 1) BRCA1/2 mutation carriers (N = 30); 2) non-carriers (N = 60); and 3) women who could not undergo genetic testing due to the absence of a known mutation in the family (N = 53). Although women identified as BRCA mutation carriers reported higher breast cancer distress levels than those who could not undergo testing, they also showed significant decreases in state-anxiety at the 12 month mark compared to the women who could not undergo testing (Meiser et al.).

A later study by Geirdal et al. (2005) compared psychological distress levels among unaffected women (N = 239) at-risk for HBOC or hereditary non-polyposis colorectal cancer (HNPCC) who could not undergo genetic testing (due to the absence of a mutation in the family) to unaffected women identified as carriers of a BRCA mutation (N = 68) and unaffected women in the general population (N = 10,000). Questionnaires to assess for psychological distress were completed three months following a genetic counselling session. Their findings revealed significantly higher anxiety and depression levels among the unaffected women in the HBOC group (N = 176 - who could not be tested) when compared to the BRCA mutation carriers. Anxiety levels were also significantly higher in those who could not undergo testing when compared to those in the general population.

How Affected Women Cope with an Uninformative Negative Result

Although the present study focused on the experiences of unaffected women living with risk for HBC in BRCA1/2 mutation negative families, a review of studies that explore how affected women cope with an uninformative negative test result is presented for comparison purposes. A few qualitative researchers have explored how affected women react and cope with an uninformative negative result. Maheu (2005) found that most of the women in her qualitative study (N=21) expressed a lack of relief after learning that a mutation was not found. The lack of relief that these women experienced stemmed from their desire to know why they had cancer, why there were so many cancers in the family, and whether they could have passed down a mutation to their offspring. Furthermore, many of the women felt that living with uncertainty when a mutation is not found creates more stress than knowing there is an inherited mutation (Maheu). In other qualitative studies, affected women who underwent genetic testing and learned that a mutation had not been found expressed a wide range of emotions that included: relief, disbelief, elation, feelings of uncertainty, and in some cases disappointment, frustration and even anger (Claes et al. 2004; Frost et al., 2004; Hallowell et al., 2002).

The lingering feelings of uncertainty in relation to one's breast cancer risk when a mutation is not identified may cause some women to refer to themselves not as healthy or ill, but as "at-risk". Labeling of oneself as being "at-risk" in relation to HBC was defined by several affected women in a study by Maheu (2009) as a chronic threat which reminded these women of the potential for cancer to strike a family member at any time. This feeling that cancer could return and disrupt their lives prompted many women in this and a study by Hallowell, Foster, Eeles, Ardern-Jones and Watson (2004) to remain focused on the present which was described as the "eternal present" (Maheu).

Keeping in mind the potential for cancer to strike a family member or themselves at any time may have hastened some affected women to assume the role of guardian in matters of cancer within the family. Maheu (2009) found that several affected women (N = 20) in their study assumed this position. In this role, many women felt an obligation to undergo genetic testing so that they could inform and protect family members who were not eligible for testing. This role was also assumed through the women's tendency to monitor the screening behaviours of their siblings and other extended family members (Maheu). However, in an attempt to give family members and themselves a genetic explanation for the multiple cancers in the family, researchers have shown that women who undergo testing often experience mixed feelings when a mutation is not found. Personal relief that is gained through the absence of a harmful mutation can also be met with frustration and disappointment in that this information does not help relatives with their health management decisions (Hallowell et al., 2002; Claes et al. 2004).

How At-Risk Unaffected Relatives Experience Living with an Increased Breast Cancer Risk in the Absence of a Known Mutation

To date, the experiences of at-risk unaffected relatives living with an elevated risk for breast cancer in the absence of a known BRCA1/2 gene mutation in the family has received little attention. The literature search conducted for this study identified five studies that explored how unaffected women perceive their elevated hereditary breast cancer risk and how living in these moderate to high risk families impacts their quality of life, self-identity, and medical decisions. One of the studies used a quantitative approach while the remaining four utilized qualitative approaches. These studies were conducted in the United States, the Netherlands, and the United Kingdom. Two of the studies conducted in the United Kingdom reported on findings from the same sample of unaffected women. All of the participants in the studies were female and sample

sizes ranged from 20 to 39 participants. The age of the participants ranged from 22 to 73 years and recruitment took place either at a cancer genetics risk clinic, a breast cancer clinic, or through affected women who had undergone genetic testing.

Although most of the participants in these studies were unaffected women, the genetic backgrounds of the women in these samples varied. For instance, the studies by Appleton et al. (2000) and Underhill et al. (2012) combined responses from unaffected women identified as carriers of a BRCA mutation, those living in families where a BRCA mutation existed, and those living in families where a mutation was not found. Incidentally, more than half of the unaffected women in the Underhill et al. study had undergone genetic testing. In the Kenen et al. (2002a; 2003b) studies, most of the unaffected women in their sample found out during an appointment at a cancer genetics risk clinic that they were not eligible for genetic testing. This finding brings into question the level of risk for many of the women in this study. Lastly, in the study by Vos et al. (2011), the authors combined the responses of unaffected and affected untested female relatives. On the one hand, combining the responses of women with varying genetic backgrounds can reveal similarities in relation to how living with risk for HBOC is experienced by women. While on the other hand, combining the responses of women with various genetic backgrounds may conceal or give little attention to aspects of an experience that would be salient and unique to a more homogenous population of women.

In terms of methodologies used, one study was quantitative and four studies used a qualitative approach. Vos et al. (2011) used a questionnaire in their retrospective descriptive study. One of the main limitations of this study was the small sample size (N = 12 untested relatives in uninformative negative families and N= 27 untested relatives in unclassified variant families). Additionally, sample bias was possible given that the probands (affected women who

underwent genetic testing) decided which relatives the researchers could approach during the recruitment phase. Out of the four qualitative studies identified, two studies (from one sample of participants) used an inductive qualitative design that adopted tools from grounded theory, one study used hermeneutic phenomenology, and one study used a telephone focus group methodology. In the Appleton et al. (2000) study, although a follow-up questionnaire was used to clarify the opinions expressed in the telephone focus groups, the topics that were discussed may have been influenced by dominant participants – potentially biasing the opinions toward those who were more vocal. In the exploratory study by Kenen et al. (2003a; 2003b), the authors adopted tools such as coding from grounded theory to identify recurring patterns, processes and relationships within the data. Twenty-one participants were interviewed on one occasion and there was no mention of member validation. Lastly, in the Underhill et al. (2012) study, a hermeneutic phenomenological approach was used to analyse the transcripts from face-to-face and telephone interviews. Twenty women were interviewed on only one occasion and a summary of the common themes was sent to all of the participants near the end of the analysis. However, only 4 participants provided feedback on the themes. Credibility could have been strengthened had all or many of the participants engaged in more than one interview to: validate preliminary themes, clarify any ambiguities; and delve deeper into their experiences. See Table 1 for a detailed summary of each of the five studies. In the next section I elaborate on the findings.

Table 1 Study Summaries					
Author Country	**Purpose**	**Sample**	**Design**	**Results**	**Implications & Comments**
Vos, Jansen, Menko, van Asperen, Stiggelbout, & Tibben, 2011 The Netherlands	To examine how learning of an affected family member's unclassified variant (UV) or uninformative negative (UR) DNA test result impacts the lives of unaffected female relatives and their perception of cancer risks.	Recruited untested female relatives through consent of affected women (probands) who had undergone BRCA1/2 DNA testing. Cancer risk for participating unaffected relatives was moderate. Sample included: 13 probands with a UV result and 27 of their untested female relatives and 5 probands with a UR result and 12 of their untested female relatives. Out of the total population of untested female relatives (N=39), eight of the untested relatives	In this quantitative retrospective descriptive study, a questionnaire was used to assess for: the untested relative's perception of the communicatio n process as well as the impact of knowing the result on their quality of life, perception of cancer risk, and medical decisions.	The combined results revealed: ■low psychological distress levels (mean 29.3); ■high quality of life scores (mean 15.3); ■54% reported ongoing participation in surveillance measures under the direction of a physician; and ■82% reported performing breast self-examinations. Communication between the proband and untested relative that was reassuring and understandable predicted the relative's understanding of cancer risk. An adhoc analysis revealed differences between the two groups. Compared to the untested relatives in families with a UV result, those relatives learning of a UR result participated less in surveillance activities (36% vs 71%) and underwent less risk-reducing surgeries (8% vs 26%). Untested relatives learning of a UR result also reported a lower personal cancer risk score than those untested relatives living in families with a UV result.	The findings imply that communication processes between the proband and relatives does matter. The findings suggest that the untested relatives learning of a UV perceived this result as more pathogenic than those learning of a UR result. These findings need to be validated in larger studies due to the small sample size. The responses of unaffected and affected untested relatives with a UV or UR in the family were combined. Given that eight of the untested relatives had

Table 1 Study Summaries					
Author Country	**Purpose**	**Sample**	**Design**	**Results**	**Implications & Comments**
		had a personal history of breast cancer. Additionally, four of the affected and four of the unaffected relatives had undergone a prophylactic mastectomy.			a personal history for breast cancer, the number of affected relatives learning of a UR result in the family is unknown.
Appleton, Fry, Rees, Rush & Cull, 2000 Edinburgh	To explore the long-term psycho-social consequences of being aware of an increased risk for breast cancer.	Twenty-five unaffected women were recruited through a familial breast cancer clinic. These women attended the clinic for at least 2 years and their lifetime breast cancer risk was between 20 and 40%. Out of the 25 participants, 2 reported a BRCA mutation in the family and 1 reported waiting	Qualitative approach using a telephone focus group methodology. A feedback questionnaire was used to clarify opinions raised in the focus groups.	**Psychological and behavioural adaptation**: fluctuating emotional and cognitive responses were triggered by certain events – i.e. screening appointments or reaching an age when a relative experienced cancer. **Cognitive strategies** used to cope with heightened worries included: adoption of a positive attitude and concentrating on the present. The adoption of healthy lifestyle behaviours helped the women to feel a sense of control over their risk. However, a few women reported chronic worry about their risk that was experienced daily. **Family Issues**:Being able to openly discuss breast cancer risk with other	The findings suggest that for some women, psychological interventions would be beneficial to address chronic worries related to breast cancer risk. These findings need to be validated in larger studies due to the small sample size. It is not clear whether genetic testing had been conducted in at least one affected family member in all

Table 1 Study Summaries					
Author Country	**Purpose**	**Sample**	**Design**	**Results**	**Implications & Comments**
		to find out the result of an affected family member. Age range: 27 to 51 years.		family members resulted in closer relationships. Concerns were raised about the increased risk that was passed down to their children. **Peer Support:** Many women recommended the availability of a support group either in person or on-line to share experiences with others in similar situations. **Provision of Information**: Being knowledgeable about their risk helped some of the women to cope with certain decisions and decreased their anxiety. However, some of the women found having this knowledge added to their present concerns.	of the families. The responses of women who reported an existing BRCA mutation in the family were combined with responses from women who are not aware of a mutation in the family.
Underhill, Lally, Kiviniemi, Murekeyisoni, & Dickerson, 2012 USA	To explore how women living with high risk for HBOC impacts their self-identity and how they care for themselves.	Out of the twenty unaffected women participating in this study: 11 had undergone genetic testing, 4 were carriers of a BRCA 1/2 mutation and 7 reported no gene mutation in the family. Age range: 22 to	Qualitative approach using interpretive hermeneutic phenomenology. In-depth face-to-face interviews.	**Identifying self**: formation of their self-identity was influenced by certain relationships with family members or friends. **Constructing risk beliefs and decisions from the context of cancer experience:** Comparing themselves to other family members with cancer influenced the decisions they made to manage risk as well as the meaning of breast cancer risk. **Anticipating a cancer diagnosis:** these women grieved over actual and potential losses in relation to their	The findings suggest that familial experiences with cancer influenced the participant's self-identity as well as their adoption of self-care strategies. These findings support a recommendation to provide for time at a clinic appointment for women to talk about

Table 1 Study Summaries					
Author Country	**Purpose**	**Sample**	**Design**	**Results**	**Implications & Comments**
		73 years. Recruitment took place at a high risk breast cancer risk reduction and prevention program.		breast cancer risk. **Facing my risk by being proactive:** all of the women thought that a person's lifestyle influences cancer risk. Some of the women tried to take some control of their risk by engaging in healthy lifestyles and reducing stress in their lives. **Managing risk through a high-risk program:** attending a surveillance appointment at a cancer centre triggered recollections of familial cancer experiences. However, being followed by experts in breast cancer provided these women with feelings of comfort and relief. Overall, the constitutive pattern that emerged was: **Living My Family's Story.** For these women, the forming of their self-identity and beliefs about breast cancer risk were influenced by familial experiences with cancer.	their perceptions of their experiences with familial cancer. Responses from women who had undergone genetic testing along with those who had not as well as those living in families with and without a known BRCA mutation were combined.
Kenen, Ardern-Jones & Eeles, 2003a UK	To explore how family cancer experiences and heuristics (cognitive short-cuts to make sense of	Twenty-one unaffected women were recruited following their first visit at a cancer genetics	Tools from Grounded Theory were adopted in this inductive design to analyze data	**Risk perception** was strongly influenced by their familial experiences with cancer. These women used heuristics such as availability, representativeness and illusion of control to understand and cope with their risk.	The findings point to a need to incorporate family psycho-social history into genetics counselling sessions and to educate genetics counsellors

Table 1 Study Summaries					
Author Country	**Purpose**	**Sample**	**Design**	**Results**	**Implications & Comments**
	information) influences an individual's interpretation of breast cancer genetic information.	risk clinic. None of the women were aware of a known cancer gene mutation in the family. All of the women had attended the cancer genetics risk clinic for the first time. These women were from families with at least two cases of breast or ovarian cancer. Age range: 24 to 61 years	collected from interviews with twenty-one participants.	**Availability**: memories of familial experiences with cancer that were sad influenced their perception of risk for breast cancer **Representativeness**: identifying with an affected family member – i.e. having a family resemblance or experiencing a family member's death or recovery due to cancer impacted a woman's perception of her own risk **Illusion of control**: although many women held the belief that healthy lifestyles and participation in screening programs could help to control their risk, many acknowledged that there was no scientific evidence to suggest that a healthy lifestyle will certainly prevent cancer in families where an inherited mutation is suspected.	about the impact of heuristics on the perception of risk. Given that most of the women, for reasons not disclosed, were not eligible for genetic testing, it is difficult to know whether or not these women are considered to be at high risk for hereditary breast cancer.
Kenen, Ardern-Jones & Eeles, 2003b UK	To explore how women at an increased risk for HBOC live with a heightened awareness of risk.	Same sample of women as in Kenen, Ardern-Jones & Eeles (2003a) N=21	Tools from Grounded Theory were adopted in this inductive design to analyze data collected from interviews with	**Family history and saliency of risk**: women with many cases of breast/ovarian cancer in the family or those with mothers and/or sisters who had died from cancer or were currently being treated tended to experience their risk more deeply than those with less cases in the family or those with survivors in the	For many women, engaging in various lifestyle and stress reduction coping strategies helped to alleviate worry and/or anxiety attached to hereditary breast cancer risk. The

Table 1 Study Summaries					
Author Country	**Purpose**	**Sample**	**Design**	**Results**	**Implications & Comments**
			twenty-one participants.	family. **Life stage and risk perception**: Awareness of the saliency of their risk was acute in younger women with children. They were concerned that they might not be alive to see their children grow up. Older women with grown children were equally concerned about their risk as they were for the risk passed down to their grand-children. **Biographical interruptions and Getting on with their lives:** Biographical disruptions were described as events where a close family member was diagnosed with breast or ovarian cancer. These events impacted the women's sense of self. Although many women were aware of their risk as becoming part of their self-identity they expressed a need to put this part of their identity aside at times in order to get on with everyday living. **Controlling chronic risk through lifestyle practices, health care choices and beliefs:** A healthy diet, stress reduction, and a positive attitude were strategies that some of the women thought might protect	women's stories also revealed a chronic risk cycle that women enter into when participating in surveillance programs. In this cycle, women experienced worry and relief. Overall, the findings reveal how a woman's perception of risk for breast cancer can fluctuate over time – depending on the events they experience that are related to cancer. Given that most of the women found out they were not eligible for genetic testing and reasons for this were not disclosed, it is difficult to ascertain the level of breast cancer risk among the women in this study.

Table 1 Study Summaries					
Author Country	**Purpose**	**Sample**	**Design**	**Results**	**Implications & Comments**
				against cancer. Participating in breast/ovarian cancer surveillance practices was expressed as another way of controlling risk. Although worries increased as the women got closer to a screening appointment, their worries were met with relief upon receiving negative results. Although most of the women in this study were not eligible for genetic testing, many thought about it as a test they might want to pursue in the future. **Prophylactic mastectomy and/or oophorectomy**: Women with young children tended to be more open to the possibility of undergoing a risk-reducing surgery. However, this decision was tied to a positive genetic test result. **Trust in medicine/science and future scientific breakthroughs versus fatalistic views**: Whereas some of the women had great faith in science and the possibility of future cures for cancer, a few women were not as hopeful.	

The findings from the studies presented above suggest that living with chronic breast cancer risk and the familial context does impact a woman's perception of her risk, level of worry, and the forming of her self-identity. Appleton et al. (2000) explored the long-term impact of living with an elevated risk for breast cancer among a group of unaffected women (N = 25) who had participated in a breast cancer clinic for at least two years. In this study, although most of the women spoke of how their anxiety and stress in relation to their elevated breast cancer risk fluctuated, a few women experienced severe worry and intrusive thoughts related to breast cancer on a daily basis. For most of the women, certain events such as screening appointments, media reports, and illness in the family triggered heightened emotional and cognitive responses in relation to their risk for breast cancer. For example, while several women in the Appleton et al. study described changes in their emotions as they got closer to a yearly mammogram appointment, some of the women in the study by Underhill et al. (2012) expressed how vulnerable they felt when they were approaching a screening appointment. One woman described in the Underhill study how waiting for an MRI result felt like a space in time where her life was in a holding pattern.

For some of the women, the age in which a relative was diagnosed with breast cancer was a marking in time that increased their fears or worries about their breast cancer risk and was described as a time bomb or a big shadow. However, moving beyond the age, in which a relative was diagnosed, cancer-free resulted in a decrease in the fear and worry leading up to that point in time (Appleton et al.). Similarly, Underhill et al. (2012) found that some of the women in their study spoke of the age that a close relative was diagnosed with cancer as a "danger zone" that they needed to surpass.

Additionally, the saliency of a woman's breast cancer risk was associated in three of the reviewed studies with factors such as: sad memories of cancer experiences in the family, the number of relatives in their family who were diagnosed with cancer and the outcome of their disease, the closeness these women felt to certain family members, and the life-stage they were experiencing (Kenen et al. 2003a; Kenen et al. 2003b; Underhill et al. 2012). For instance, in the study by Kenen et al. (2003b), where twenty unaffected women at an elevated risk for breast cancer were interviewed after their first visit at a cancer genetics risk clinic, a more heightened awareness of cancer-risk was expressed by those who knew of several family members diagnosed with breast/ovarian cancers or those who had first degree relatives who had died from cancer compared to those who knew of either fewer relatives diagnosed with cancer or relatives who survived cancer. Some of the younger women with children in this study also expressed how concern for the possibility of not being alive to raise their children intensified the importance of their breast cancer risk (Kenen et al. 2003b).

In two of the reviewed qualitative studies, many women associated the formation of their sense of self with the connections they had with family members and the experiences they had with cancer in the family (Underhill,et al. 2012; Kenen, et al. 2003a). It was through these connections that several women in the Underhill study identified a life purpose that was often defined as being there for other family members. Wanting to be there for others, especially for young children, influenced the way these women cared for their health. Although their breast cancer risk was a part of their self-identity, some of the women spoke of a need to try to put aside their breast cancer risk in order to get on with their lives. There was recognition among some of the women of how living with fear and worry related to the possibility of developing breast cancer could overwhelm and take over their lives if they let it (Kenen et al. 2003a).

Taking control of their breast cancer risk through lifestyle choices and healthcare practices was also described by the women in the reviewed studies as important ways to lessen their worries and cope with their risk. The practice of positive thinking, learning about issues related to cancer, participation in breast cancer screening, cognitive avoidance, maintaining a healthy diet and reducing stress are some of the coping strategies identified by the women in these studies to adapt and feel more in control of their cancer-risk (Appleton et al. 2000; Kenen et al. 2003b; Underhill et al. 2012). Even though many women expressed that being followed through a breast cancer screening program was worrisome, there was comfort in knowing that they were being followed by experts who would be able to detect cancers and provide swift access to treatments when necessary. Additionally, several women in these studies expressed gratitude toward the type of technology and expert care that was available to them through the cancer screening clinics (Underhill, et al.; Appleton, et al.; Kenen, et al. 2003b). Moreover, the feeling that they were being cared-for that emerged from the experiences of several women in the Underhill et al. study when they talked about their relations with experts at a high risk breast cancer clinic brought them a sense of relief.

Summary of the Literature

The preceding literature review provided an overview of what we know about women living in families where genetic testing has been conducted in an affected family member and no known BRCA1/2 genetic mutation has been identified. For many affected women undergoing BRCA genetic testing, learning of an uninformative negative DNA test result is not reassuring (van Dijk, Otten, Tollenaar, van Asperen & Tibben, 2008; van Dijk et al., 2005; Cypowyj et al., 2009). Interestingly, it is the view of some affected women that living with uncertainty when a mutation is not found can be more stressful than knowing of an inherited mutation (Maheu,

2005). Affected women learning of their uninformative negative DNA test result may react to this knowledge with a wide range of emotions that include: relief, frustration in not knowing what could be causing so many cancers in the family, disbelief, disappointment, and/or even anger (Claes et al. 2004; Frost et al., 2004; Hallowell et al., 2002).

Unaffected women living in families where a known mutation was not identified have been found to have higher anxiety/depression levels than those who were carriers of a BRCA mutation (Geirdal et al. 2005). Qualitative studies suggest that anxiety and depression of these women may be influenced by family cancer experiences. These experiences appear to impact the forming of a woman's sense of self as well as her understanding and interpretation of her cancer risk. The studies also described strategies used by unaffected women to adapt and cope with their risk such as: participation in breast cancer screening programs, maintaining a positive attitude and a healthy diet, cognitive avoidance, and finding ways to reduce stress (Appleton, et al. 2000; Kenen, et al. 2003a; Kenen, et al. 2003b; Underhill, et al. 2012).

Although these studies have added to our understanding of the experience of unaffected women, there is a paucity of research in this area. Just as there are studies that have focused specifically on the experiences of unaffected women identified as carriers of a known BRCA mutation in order to identify aspects that are unique to this population of women, future research should focus specifically on the experiences of unaffected women who cannot undergo genetic testing due to the absence of a known mutation in the BRCA 1/2 genetic testing of an affected relative. Furthermore, given that only one of the reviewed qualitative studies used a hermeneutic phenomenological approach to uncover meanings related to living with risk for HBOC in a group of unaffected women with a mixed genetic background, it is beneficial to use this approach in a future study in a more homogenous group of unaffected women. Therefore, the focus of the

present hermeneutic phenomenological study was to explore how unaffected women, living in families where genetic testing did not identify a known mutation in an affected relative, experienced living with risk for hereditary breast cancer.

CHAPTER 3 - METHODOLOGY

Hermeneutic phenomenology is a philosophical examination of the lived experience. A primary aim of van Manen's hermeneutic phenomenological approach is to encourage a sense of wonder and tacit awareness through a "description of the experiential meanings we live as we live them" (van Manen, 1990, p. 11). The aim of van Manen's hermeneutic phenomenological approach is to come into contact with the lived experience through descriptive and interpretive representations of an experience. This approach fits well with my research question: *How do unaffected women with at least a 20% lifetime risk for breast cancer experience living with risk when a BRCA1/2 mutation has not been found in the family?* Given that van Manen's interpretation of phenomenology is influenced by the writings of several philosophers, I begin this chapter with a brief history of hermeneutic phenomenology to trace its roots and to locate its philosophical assumptions. I then discuss van Manen's hermeneutic phenomenological method and explain how I used it in this research project.

A Brief History of Hermeneutic Phenomenology

To gain an appreciation for the transformative philosophical nature of phenomenology, I now discuss the major contributions of Husserl, Heidegger, and Gadamer to show how the writings from these philosophers developed and later transformed phenomenology to include the art of hermeneutics. The etymological origin of the word phenomenology comes from the Greek words: "phainomenon" and "logos". The meaning of the Greek word – "phainomenon" – is "to show oneself", whereas the word "logos" – was originally understood as a "word" or "thought" (Moran, 2007). The term hermeneutics originated from the Greek mythical god named Hermes, whose role was to interpret and deliver messages from the gods to mortals (Kelley, 1983).

Edmund Husserl

Edmund Husserl, known as the father of phenomenology, was a German phenomenologist and mathematician. He introduced phenomenology at the turn of the twentieth century as a philosophical practice to explore the essential meaning structures of all phenomena as it is consciously experienced. The aim of Husserl's phenomenology was to obtain a pure description of phenomena as it appears in the consciousness of the experiencer (Moran, 2007).

The philosophical tenets of Husserl's phenomenology hold a primary concern for the analysis of consciousness and the intentionality of the mind to external objects. Husserl's thoughts on intentionality and consciousness are derived from the philosophical positivist traditions of Descartes, Hume and Kant, where the human condition is viewed as subject that is external to a world of objects – which came to be known as Cartesian dualism. Descartes' notion of dualism came from his question about how we can be certain of what we know as the truth. As he wrestled with this question, he came to understand the external world as separate from consciousness and proposed that subjectivity – known as human thought – is separate from matter (an extension of thought). To Descartes, to *be* is thought, for he believed that we can exist without a body but not without consciousness awareness. This epistemological standpoint had a profound influence on the way knowledge is generated in the human sciences - leading researchers to believe that one can somehow objectively explore phenomena from a detached viewpoint. It was this representation of reality being constructed within the mind that philosophers such as Heidegger and Merleau-Ponty tried to change through their writings about human beings as embodied agents fully engaged in the world (Magee, 2000; Taylor, 2005).

Martin Heidegger

Martin Heidegger is regarded as one of the great existential phenomenologists of the twentieth century. Born in Germany in 1889 and raised in a Catholic family, Heidegger's early education in theology was grooming him to become a priest. During the time Heidegger was studying theology at Freiburg University, he read and became fascinated by the writings of Husserl about phenomenology. Husserl's writings inspired Heidegger to change his direction to study philosophy for his doctorate and to become a phenomenologist. Along with Husserl, the philosophies of Brentano (Husserl's teacher), Kierkegaard, and Nietzsche greatly influenced Heidegger's thinking. In Heidegger's seminal work entitled: "Being and Time" he investigates a question that becomes his life's work – the re-examination of the meaning of Being. It was through his exploration about the meaning of Being that Heidegger rejected many of the notions Husserl held about phenomenology and transformed the philosophical practice to include hermeneutics to understand the nature of being (Moran, 2007).

Contrary to the views of Husserl, Heidegger believed that consciously directed actions usually exist only when something breaks down – such as when the mind is directed to the hammer that is not working properly. He proposed that for the most part, human beings go about daily practices without conscious awareness of the objects with which they interact. For example, the illustration of the hammer in Heidegger`s lectures demonstrates the transparency of coping within our world as the carpenter uses the hammer while thinking about something else. Just as I may open a door without consciously thinking through the process that is used to lift my hand to the knob and turn the handle, the carpenter will likely use the hammer without conscious awareness of how hard to hit the nail or how deeply the nail must penetrate the wood. Husserl may counteract this notion with the thought that we must consciously come to know that the

hammer *is* a hammer, whereas Heidegger would argue that if we are to believe that human beings are part of and situated within a world of objects rather than as observers detached from objects, we can see how the way that we may cope with the daily use of the hammer becomes transparent and unconscious until the hammer breaks down and we become conscious of the hammer and its significance (Magee, 2000).

In addition to differing beliefs in regard to intentionality, Husserl was interested in epistemological questions that looked at how we know what we know whereas Heidegger moved toward ontological questions to re-examine the meaning of Being. For instance, Husserl believed that the phenomena experienced by the participant could be objectively understood by the researcher through the bracketing (setting aside) of one's preunderstandings (Moran, 2007). The idea that one can separate prior understandings of a phenomenon to understand it in its purest form is a post-positivistic Cartesian view that was rejected by Heidegger, for he believed that it is impossible to separate the knower from the known (Dreyfus, 1991).

Heidegger's movement toward ontological questions to understand what it means to *be* in the world in order to understand how we make sense of the world of which we are already and always a part of, was a turning point referred to as the "interpretive turn" that moved beyond descriptive phenomenology to include the art of hermeneutics (Leonard, 1994). Heidegger was the first to put forth the terms hermeneutic and phenomenology as a philosophical approach that views understanding of an experience as an interpretation that blends the background understandings of the participant and the researcher (Koch, 1995; Heidegger, 1962).

I understand the term "background understandings" to be a filter to make sense of the world that exists before we are born – a filter that stems from the language, cultural practices, and historical situation into which we are thrown (Koch, 1995). This lens, of which we are

mostly unaware, is not static for it changes with experiences of our being-in and being-with others in the world. Although Heidegger believed that we are mostly unaware of the background understandings as we engage with others in everyday living, it is through these filters that the meaning of that which is disclosed may be articulated within a hermeneutic phenomenological inquiry. At this juncture, it is important to understand Heidegger's three-fold structure of interpretation from which meaning is derived. As Heidegger (1962) writes: "Meaning is the upon-which of a projection in terms of which something becomes intelligible as something; it gets its structure from a fore-having, a fore-sight, and a fore-conception`` (p. 193).

According to Heidegger (1962), a fore-having speaks to our background understanding of an object/situation which is founded in "something we have in advance…which is already understood". Our background understanding of the problem at hand is not explicit and determines the type of questions that may be asked. A fore-sight pertains to the belief that an interpretation is founded in "something we see in advance". In this sense, an interpretation is derived from a particular point of view. Finally, a fore-conception grounds the interpretation in "something we grasp in advance". In this sense, the inquirer always has an expectation for what will be known (p. 191; Dreyfus, 1991). Thus, in view of the belief that the hermeneutic phenomenologist is always projecting meanings onto the text through these fore-structures of interpretation, the quest of the inquirer is to work out her/his projected understandings by constantly going back to "the things themselves" (Dreyfus, 1991, p. 200).

The outcome of these structures of interpretation is to arrive at an understanding that draws to the surface layers of meaning within a woman's everyday experience of coping with uncertainty in relation to her elevated hereditary breast cancer risk. The act of bringing to the surface that which is often hidden within human experience is a central and unique tenet of

Heideggerian hermeneutic phenomenology that is made explicit as the researcher interprets the text to understand how an individual's lifeworld influences her/his reality (Lopez & Willis, 2004). The interpretive process that intertwines the realities of the individual with her/his world was presented by Heidegger as the hermeneutic circle. Heidegger perceived the hermeneutic circle as a primordial way of existing – proposing that human beings and world exist within a circle of interpretations (Hoy, 1993).

The term "world" in the Heideggerian sense, is not associated with the environment or nature, rather it is described as "the meaningful set of relationships, practices, and language that we have by virtue of being born into a culture". The world in which we are engaged "is both constituted by and constitutive of the self" (Leonard, 1994, pp. 46-47). Thus, it is through this circular interpretive relation between the self and world that we may come to understand who we are and who we can become through the possibilities that are presented by the world from which we are "situated" or "thrown" (Leonard). As a way to interpret textual representations of experience, Heidegger later went on to extend our understanding of the hermeneutic circle as a practice that uncovers meanings that are co-constituted through the blending of background understandings held by the researcher and the participant.

Hans-George Gadamer

Hans-George Gadamer was a student of Heidegger and is credited with the development of philosophical hermeneutics. He built upon the beliefs of Heidegger to claim that "language and history supply the shared sphere in the hermeneutic circle" (Koch, 1996, p. 176). For Gadamer, hermeneutics is a way to understand the other and the self through the fusion of horizons. The fusion of horizons "is another metaphor for understanding" (p.176). It is through

the merging of horizons that the background understandings of each person in the hermeneutic circle unite to confer a new meaning (Moran, 2007; Taylor, 2011).

The acceptance of background understandings as a lens to understand and interpret new understandings through a back and forth dialogue between researcher and participant is why the questions themselves are of utmost importance (Gadamer, 1975). Gadamer beckons us to think of opinion as a way to suppress questions, for when we ask questions from a stance of knowing – we find ourselves unable to be open to the other's perspective about their experience. In other words, asking questions in order to prove that we are right about a particular topic will not provide us with insight. Therefore, as Gadamer points out, to gain insight and to be open to the experience of the other, "one must want to know – which involves knowing that one does not know" (p. 326).

Coming to van Manen

As I read some of the philosophical writings from several phenomenologists, I came to the realization that I resonate with the epistemological and ontological views of Heidegger and Gadamer. However, the philosophical beliefs I share about how we know what we know and the nature of reality does not provide me with a rigorous and thoughtful way to conduct a hermeneutic phenomenological study. I chose Max van Manen's hermeneutic phenomenological method to guide this research because his approach is also rooted in similar philosophical assumptions of Heidegger and Gadamar. For example, van Manen's (2007) writings reveal a worldview that suggests how we know what we know is a dynamic and complex way of being that does not come from a standpoint of detachment. He refers to the writings of Heidegger (1985) about knowing as "a mode of being of in-being" (p.161). The term "in-being" is described by van Manen as our "everyday being-involved-with the things of our world" (p.13).

Moreover, his writings also reveal an ontology that is based on the assumption that there are multiple realities. A phenomenological description is but one interpretation that derives from the context of one person. In a phenomenological inquiry, there is always the possibility of "yet another complementary, or even potentially richer or deeper description" (van Manen, 1990, p. 31).

Max van Manen is a Professor Emerita in the Faculty of Education at the University of Alberta in Edmonton, Alberta Canada. For over two decades, van Manen's hermeneutic phenomenological approach has been utilized to understand the human experience by phenomenologists in professional disciplines such as: education, nursing, medicine, and psychology. His philosophical approach to understand human experience draws from phenomenology, existentialism, and hermeneutics. It is van Manen's (2014) belief that "phenomenology is, in some sense, always descriptive and interpretive, linguistic and hermeneutic" (p. 26). I agree with van Manen (1990) when he says that phenomenology starts and ends with the lived experience. The aim of a phenomenological inquiry is not to study one's opinions or beliefs about a topic – it is a project that attends to and describes pre-reflective human experience. The term pre-reflective refers to "the ordinary experience that we live in and that we live through for most, if not all, of our day-to-day existence" (van Manen, 2014, p. 28). It is also a hermeneutic and a linguistic project in that the texts from these lived experiences are interpreted to uncover the meanings embedded in everyday human existence and the language we use brings us into contact with the lived experience (van Manen, 1990)

van Manen's Hermeneutic Phenomenological Method

As an approach to gain a deeper understanding of everyday lived experiences, van Manen's hermeneutic phenomenological method provided guidance as I delved deeply into the

mystery and wonder of human experience. I used the following principles as outlined by van Manen (1990), to conduct this research:

1. Turning to a phenomenon which seriously interests us and commits us to the world;
2. Investigating experience as we live it rather than as we conceptualize it;
3. Reflecting on the essential themes which characterize the phenomenon;
4. Describing the phenomenon through the art of writing and rewriting;
5. Maintaining a strong and oriented pedagogical relation to the phenomenon;
6. Balancing the research context by considering parts and wholes (p. 30-31).

Recruitment, Research Setting and Sample

Prior to the recruitment phase of this study, I gained an experiential understanding of the issues and experiences of women who are at-risk for hereditary breast and/or ovarian cancer (HBOC), by observing several consultations at an HBOC and genetics clinic in Western Canada. Although I primarily listened to the consultations with patients and other family members at these clinics, there were opportunities for me to gather family cancer histories to construct a few family cancer pedigrees. I also consulted with members of the high risk team as well as a geneticist and genetics counselor outside of the clinics to find out more about their roles and experiences with these women and to ask questions about breast cancer genetics. Recruitment occurred at an HBOC clinic in Western Canada. During the recruitment phase of this study, the comprehensive breast health team at the HBOC clinic was following 669 women who were between 25 and 70 years of age and were identified as having at least a 20% projected lifetime risk for breast cancer. The team consisted of: a radiation oncologist, an oncology breast surgeon, an oncology gynecologist, a registered nurse coordinator, and a pharmacist. Of the 669 women participating in the clinic, 57 women were identified as having no personal history of cancer and living in a family where an uninformative negative result was identified in the genetic testing of affected blood relatives (personal communication, S. Holzmann).

Purposive sampling was used to recruit unaffected women at-risk for HBC through an HBOC clinic in Western Canada. In phenomenological research, the term purposive refers to the identification of participants who are articulate and want to share their story (van Manen, 1990). For this study, I met with the nurse coordinator at the HBOC clinic to give her an outline of the inclusion criteria (see Appendix B) and copies of the letter of introduction to give to potential participants at the beginning of their clinic appointment (see Appendix C). In addition to a willingness to share their story, the women in this study met the following inclusion criteria:

- female, between 25 and 70 years of age
- has no previous personal history of cancer and has not undergone BRCA genetic testing
- is identified as having at least a 20% lifetime risk for breast cancer
- has at least one 1st or 2nd degree affected relative who has undergone BRCA genetic testing and has received an uninformative negative result
- a known or unclassified BRCA mutation has not been identified in the family
- speaks English
- resides within 3 hours driving distance from Edmonton

The nurse coordinator identified those women who met the inclusion criteria and placed the invitation/introduction letter about the study at the front of the women's charts. Originally, it was decided that as long as the narratives were rich in terms of its quality and depth, a sample size of between 5 and 8 women would be enough to create a vocative textual narrative that was insightful and reflective. In phenomenology, if too many narratives are sought, the writer runs the risk of developing a narrative that is shallow (van Manen, 1990).

Between July and September 2014, an invitation/introduction letter was handed to 12 women who met the criteria during a clinic appointment. Physicians attending the clinics asked the women who received an invitation/introduction to the study letter if they were interested in talking to the researcher about the study at the end of their clinic appointment. Although I

intended on meeting with a maximum of 8 women, I decided to increase the sample size to a maximum of 10 due to a very positive response from those who were approached.

Data Collection

Out of the 12 women who received an invitation/introduction letter, 10 of the women met with me at the end of their clinic appointment. During our visit at the clinic, I discussed the study more in-depth, answered their questions, read aloud the participant information letter (see Appendix D), obtained informed written consent (see Appendix E), and arranged for an appointment time and place that was convenient for them. Those who did not want to immediately talk to me at the clinic were instructed to contact me directly via the contact information given on the invitation/introduction letter. Out of the 10 women who gave written consent to participate in this study one participant did not attend a scheduled appointment time for her first conversational interview. One attempt was made by telephone to contact the participant. A return call from the participant was not received.

In this study, nine women between 25 and 58 years of age participated in conversational interviews on two or three occasions. The first two conversations took place one to four months apart. A third conversation was conducted with two women to clarify interpretations of some of their experiences near the end of the analysis of all of the narratives. These conversational interviews took place in diverse settings that included: the women's homes, work place, on campus at the University of Alberta, as well as a somewhat quiet area in a busy mall. Although all of the first conversations were face-to-face, two of the women living more than two hours from Edmonton requested and had a second conversation over the telephone.

In the first conversational interview, I read aloud an opening statement to initiate a conversation about the experience of living with HBC that was directed by the women and told

in an unfettered manner. This approach provided me with direct access into the participant's world and discouraged me from superimposing my language and presuppositions onto the subject being explored (Richards & Morse, 2007; Conroy, 2003). I used a list of guiding questions and probes when a participant needed encouragement to continue and/or in the case where these questions were not explored spontaneously in the conversations (see Appendix F for conversational interview questions). All conversations were tape recorded and all but one was transcribed by a hired transcriptionist.

Fictitious names were used in place of the participant's name in the transcripts whereas the names of places and/or events that may have identified the participant were removed from the transcript. A narrative summarizing key points discussed in the first conversation was constructed for each woman. The summaries were then emailed to each woman at least one week before the second conversation to allow time for them to read over and reflect on their own narrative summaries. As suggested by van Manen (1990), during the second conversations, I asked each woman if my summary description of their experience spoke to how they experience living with hereditary breast cancer risk and asked them to clarify any ambiguities. Outside of a few minor corrections to the information presented in some of the narratives, the women expressed that the narrative summaries captured their experience well. One woman's response to her narrative summary was - "*you nailed it*".

The use of multiple conversations between me and the participant allows both parties opportunities to reflect and elaborate upon previous conversations and to delve deeper into the experience of living with HBC risk (van Manen, 1990). I found that several women were eager to talk again and came to the second conversation with notes from their reflections about living with risk. Although I found that the second conversation I had with each woman resulted in a

deeper understanding of their experiences and helped to clear any ambiguities, when I brought the experiences of the women together in the findings chapter I noticed that there were some aspects of the experiences of certain women that I had questions about. Thus, I contacted three of the women to address my questions in a third conversation. Out of the three women contacted, one declined a request to talk again. Two women agreed to meet for a third conversation. I spoke with one woman over the telephone and met with the other woman in person. Although the primary purpose of the third conversation was to delve deeper into certain aspects of their individual experiences, I took the opportunity to read aloud excerpts from the compiled narrative and asked these women to share with me whether the descriptions resonated with their experiences.

Although sharing the text with two of the women was one way to informally test the strength and quality of my interpretations of their experiences, it was through the frequent meetings I had with my supervisor that the interpretive insights I was forming became more visible. In the beginning of the data collection period I de-briefed with my supervisor after two first conversational interviews with two participants and gave her a copy of the transcripts and narrative summaries that outlined what we had talked about along with my questions about the experiences of these women. I met with my supervisor frequently throughout the data collection and analysis/writing process to talk about how the conversations went and to discuss emerging themes.

Turning to the Nature of the Lived Experience

To understand and find meaning within the lived experience of others, I reflected on my orientation to and interest in the phenomenon being studied. My interest in the experiences of unaffected women living with HBC came from my experiences as a breast cancer survivor and

public health nurse. Even though I provided several breast health presentations to women as a public health nurse, the possibility of breast cancer in my life was but a fleeting thought until I found a lump in my 40's. It was through my experience living with a breast cancer diagnosis and reading about the history of breast cancer that a passion arose in me to learn about the experiences of others living with hereditary risk for breast cancer.

Knowing that I have experienced living with a breast cancer diagnosis and having read as much as I could to understand how other women experience living with risk for HBC, I knew that I was starting this research with preconceived views of what it can be like to experience living with this risk. In accordance with Heidegger's views, the terms "preunderstanding " or "prejudice" refers to the prejudgments that preside over our understanding of the phenomena in question. Contrary to Husserl's belief that our preunderstandings can be bracketed and therefore removed from the description and meaning of the phenomena, Heidegger espoused that it is impossible to remain completely objective in our interpretation of the phenomena (Moran, 2007).

Although van Manen (2014) agrees with Heidegger's assertion that "forgetting one's preunderstandings is not really possible", he proposes that one does need to explicate and reflect upon her/his preunderstandings in order to open oneself to the phenomena in a way that lets "speak that which wishes to speak"(p. 224). I agree with van Manen's stance on the explication of assumptions and preunderstandings and therefore wrote my preunderstandings in a field journal throughout the study. Journaling helped me to continually reflect upon and question my particular history and knowledge about hereditary breast cancer risk as I made sense of the experiences these women shared with me.

Existential Investigation

In a hermeneutic phenomenological study, the generation of data to understand more deeply the experiencing of phenomena comes from a variety of sources. I chose three of van Manen's (1990) avenues to explore and generate data. First, I wrote a description of my personal experience with breast cancer to gain an understanding of the phenomena from my perspective. Next, I collected experiential descriptions through face-to-face conversational interviews between myself and the women participating in this study. In a hermeneutic phenomenological inquiry, the use of individual face-to-face conversations between the researcher and participant signifies a partnership wherein each party comes into the hermeneutic circle to understand the lived experience more deeply (van Manen). It is important to note that although the terms "conversation" and "interview" are sometimes used interchangeably in qualitative research, I draw a distinction between the two terms. It is my belief that an interview sets the stage for a conversation where I, the interviewer, will direct the interview with a set of questions. In the conversational interviews that were conducted in this study, the aim was to create an open space for each woman to take the lead as she talked about and described her experiences (Bergum, 1989).

In addition to the above avenues to explore and generate data, as I read the transcripts of my conversations with each woman, I identified certain terms/idiomatic phrases related to living with risk and explored their original meanings through etymological sources. Hermeneutic phenomenologists also look to other phenomenological writings on the phenomenon of interest to gain insights from the interpretive descriptions of others experiencing the phenomenon (van Manen, 1990). I conducted a library search using CINAHL, PsychInfo, and Medline databases to identify phenomenological writings about living with risk for breast cancer. I also went back to

certain philosophical writings and other literature to explore some of the meanings and themes that emerged from the conversations I had with these women to see meanings from different perspectives and to help me to question the meanings within the transcripts that I was interpreting.

Phenomenological Reflection

The aim of phenomenological reflection was to try to get in touch with the essential meaning of living with risk for HBC (van Manen, 1990). This process involved two parts: conducting thematic analysis and determining essential themes.

van Manen (1990) suggests that a "theme is the experience of focus, of meaning, of point" (p. 87). A theme also gives shape to that which is being talked about. In other words, when I looked for themes in the narratives of women living with risk for HBC, I was trying to articulate an aspect of the phenomenon that was being talked about in a way that makes sense of and gives meaning to human experience. I listened several times to audio-recordings of the conversations and used different approaches as suggested by van Manen (1990) to reading the text. For this study, I chose to: 1) highlight certain phrases in the text that stood out; 2) read each sentence or a cluster of sentences to uncover thematic aspects that reveal the phenomenon being talked about; and 3) read the text as a whole to reveal overarching themes. As I read the text, I also reflected on four fundamental existential themes that are vital to the formation of the life-world and are likely to be experienced by all human beings. These existential themes include: "*lived space* (spatiality), *lived body* (corporeality), *lived time* (temporality), and *lived human relation* (relationality or communality)" (van Manen, 2014, p.302). Although these existential themes overlap in our experiences, I separated them in my analysis to understand how these

ways of being-in-the-world help to reveal meanings from within the narrative. Through the writings of several phenomenologists I now describe these existential themes.

Lived Space

van Manen (1990) writes that we move in and out of many lived spaces in our day-to-day lives – the spaces in which we dwell affects the way we feel and relate to others. The phenomenological concept of space is referred to by Heidegger (1962) as the grounding or location of one's concerns in relation to the phenomenon that is being talked about rather than the physical location of self and objects. Heidegger goes on to illustrate how we experience nearness and remoteness in space through that which concerns our being-in-the-world as he writes:

> One feels the touch of [the street] at every step as one walks; it is seemingly the nearest and Realest of all that is ready-to-hand, and it slides itself, as it were, along certain portions of one's body – the soles of one's feet. And yet it is farther remote than the acquaintance whom one encounters "on the street" at a "remoteness"… of twenty paces when one is taking such a walk (p. 141-142).

The example above by Heidegger highlights how concern brings to the foreground what matters to an individual whereas that which is near but does not cause concern becomes remote – in the background. Another way of understanding the concept of being-in-space is through our embodied orientation to space. As Taylor (1993) writes, "our world is shaped by our being bodily agents" (p. 318). Taylor speaks of our perception of a scene that is before us through the orientation of our bodies to the object that is of interest. As the body moves to the far right or far left, our understanding of that which is in the foreground changes to uncover meanings that were not disclosed when in a prior position (Taylor).

Lived Body

As a basis from which we experience and understand the world, the lived body must not be confused with Husserl's view of it as a null point – a mathematical term indicating a zero – a starting point from which the body recedes (Leder, 1990). Rather, Merleau-Ponty (1962) beckons us to view the body as "the fabric into which all objects are woven, and it is, at least in relation to the perceived world, the general instrument of my "comprehension" (p. 235). Thus, an understanding of the world and self through the body-subject emerges through the ways that "we act and move" – ways in which we are mostly unaware of as we cope and adapt to situations through shared practices and background understandings (Taylor, 1991, p. 309).

As long as our bodies are functioning well, we perceive and adapt to situations in the world in ways that mostly go undetected. But, once the body breaks down - as in the patient with Parkinsons who must focus intently on bodily movements that are normally taken-for-granted – a new way of accessing and experiencing the world is understood (Sunvisson, 2010). Hence, it is through the breakdown that we see and understand our sense of self and world through a different perspective.

Lived Time

Lived time is described by van Manen (1990) as subjective for time can be felt as speeding up, slowing down, or suspended. He also alerts us to the depth of temporality and its effect on whom we are today and who we will become tomorrow. It was Heidegger's (1962) belief that "time must be brought to light – and genuinely conceived – as the horizon for all understanding of Being and for any way of interpreting it" (p. 39). The three-fold structure of temporality beckons me to consider how the question being asked in the present – what is being

talked about – combines the past (what is already given) with the future as a new understanding is reached (Harman, 2007).

Genetic knowledge provides women with information on their ancestral past, their present and future all at once. Ancestral genetic mutations that are passed on presents a woman with future breast cancer risk to be managed in the present (Huijer, 2005). The same could be said for families where there is a strong family history of breast cancer but no sign of a known harmful genetic mutation within the family. These women may still be considered at high risk for the development of breast cancer, only their decisions in the present to reduce their risk must be based on family history alone.

Lived Relations

Lived human relations refer to our interpersonal connections with others within a shared space (van Manen, 1990; Munhall, 1994). Our relations with others can impact who we are and who we become. For example, a parent providing emotional support to a child who is experiencing anxiety creates a space in which a child feels safe and secure to explore his/her feelings. Throughout the women's stories, I reflected on the significance of their interpersonal relations with others to understand how these relations impacted how they live with risk for HBC.

As I reflected on the life existentials I wrote several draft phenomenological notes and paragraphs that were based on readings of the text. These drafts were used to develop themes and were integrated into the final descriptions of the experience. I also searched for sources of art and poetry that reflected thematic aspects of this study and included excerpts or images from these sources to illuminate meanings from perspectives outside of the narrative form. van Manen

(1990) refers to the work of a phenomenologist as being similar to the artist in that the outcome is to "grasp the essence of some experience" (p. 97).

Throughout this research, I continually reflected upon and questioned whether the themes were essential or not. To determine which themes are essential, van Manen (1990) proposes that we ask the following questions:

> Is this phenomenon still the same if we imaginatively change or delete this theme from the phenomenon? Does the phenomenon without this theme lose its fundamental meaning? (p. 107).

In this research, I imagined if the central meaning of the phenomenon was compromised or lost with the deletion of a theme. I met with my supervisor several times to discuss the emerging themes and found that our talks helped me to see new insights and to not lose sight of the research question. Once I settled on the themes to be used to shape the narrative, I wrote a narrative that encompassed meanings from all of the individual narratives.

Phenomenological Writing

Phenomenological writing is a thoughtful and reflective practice that helps the researcher to see-meaning. It is an act that attempts to show that which is concealed within the narrative (van Manen, 1990). I engaged in several important processes that include: attending to the speaking of language, varying the examples, and writing and rewriting.

van Manen (1990) suggests that it is important to remain true to the speaker. To do this, I listened thoughtfully to the undertones of language and silences within the digital voice recordings. Notes were made along the margins of the textual data to remind me of the pauses and tone of the language.

Varying the examples was employed to "make visible…that which constitutes the nature or essence of the phenomenon" (van Manen, 1990, p. 121-122). It is a way to show different

examples of ways of experiencing phenomenon within a phenomenological description (van Manen). For example, fear was a central theme for the women in this study that was experienced through their imaginings of being diagnosed with cancer. How these women experienced fear in relation to living with risk for HBC was provided through the varying of phenomenological descriptions.

The art of writing and re-writing in a hermeneutic phenomenological inquiry is a creative process wherein the phenomenologist is actively re-thinking, re-flecting, and re-cognizing the phenomena as she/he explores human experience in a back and forth movement between the parts and the whole of the text. The goal of this process was to create a finely crafted piece of writing that offers a rich, evocative, and descriptive understanding of the phenomenon (van Manen, 1990). It was through the many drafts I crafted of their experiences that experiential meanings were grasped. As I went through this experience of writing and re-writing I found myself recalling an expression from van Manen at a workshop of his that I attended last fall. His words – *the writing is the analysis* – echoed in my mind as I made contact with experiential meanings within the writing and re-writing of the text.

Evaluation Criteria to Assess the Quality of a Phenomenological Study

van Manen (2014) proposes the following criteria to assess the quality of a phenomenological study: "heuristic questioning, descriptive richness, interpretive depth, distinctive rigor, strong and addressive meaning, experiential awakening, and inceptual epiphany" (p. 355).

Heuristic Questioning

A good phenomenological text induces in the reader wonder and a questioning attunement to what the phenomenon is (van Manen, 2014). As I wrote and re-wrote descriptions

of the experiences of these women, I asked myself if the text evoked a sense of wonder and questioning.

Descriptive Richness

To achieve an experiential description that is recognizable, van Manen (2014) suggests that the researcher pay attention to the richness of the description. In this study, my intention was to create textual descriptions that are rich enough to evoke in the reader an experience that is recognizable.

Interpretive Depth

The text must offer "reflective insights that go beyond the taken-for-granted understandings of everyday life" (van Manen, 2014, p. 356). I engaged in phenomenological reflection to go beyond the taken-for-granted understandings of living with risk for HBC to uncover meanings. The insights I grasped within the narratives of these women may challenge the reader to question his/her own beliefs about living with risk for HBC.

Distinctive Rigor

Critical appraisal of the meaning of the phenomenon was achieved as follows:
(1) In order to capture the meanings within the experiences of these women, it was imperative for me to maintain an open and questioning attitude during the conversations so that I could clarify meanings, avoid misunderstandings, and provide space for the participant to reflect. To come into a conversation with an open and questioning attitude demands, as Munhall (1993, 1994) suggests, a de-centering or abandonment of one's assumptions about the phenomenon – a movement to a space of unknowing. This step was very important as I engaged in conversations with these women as well as when I immersed myself in the textual and voice data, given that I have a personal history of breast cancer and I engage in breast cancer surveillance practices.

(2) As I teased out the themes/meanings from the text and audio-tapes, I reflected on the context of each situation, existential themes, and reflective journals about my own feelings and beliefs about hereditary breast cancer risk to understand how I was coming to a certain theme and to question what it was that I was not questioning.

(3) During subsequent hermeneutic conversations, I asked each woman to read a summary narrative from the prior conversation and to comment on the preliminary meanings/themes.

(4) I met with my supervisor several times to read parts of the narratives and discuss the themes I was developing.

(5) I met with 2 of the women for a third conversation to clarify and delve deeper into some of their experiences and to read excerpts from the narrative that included the voices of all of the women to see if they resonated with any or all of the experiential descriptions. After reading excerpts from the combined narratives, one of the participants commented:

> *I think you did an excellent job…Even those things that I experience very differently from the other women, it seems like they're rooted in very similar feelings, concerns, fears, hopes.*

As another participant read about her experience and the experiences of other women, she commented: *there's always little things in each story that sort of tweak with me*.

Strong and Addressive Meaning

van Manen (2014) invites the reader to ask: "does the text "speak" to and address our sense of embodied being?" (p. 356). I understand this thought to mean that the narrative I developed and the meanings I revealed from the stories of the women in this study reveal possible ways in which we, as human beings, may engage and interact with others in the world as embodied beings.

Experiential Awakening

In a phenomenological text, the language that is used is meant to help us make contact with the pre-reflective experience as it is lived (van Manen, 2014). I paid close attention to the language I used in order to present the experience in its pre-reflective state.

Inceptual Epiphany

An inceptual epiphany is experienced when the reading of the descriptive narratives and the meanings that are revealed alters present attitudes and moral beliefs held by the reader (van Manen, 2014). Although I cannot speak for the experiences of all readers of this research, I can state from my own experience that my prior assumptions about how unaffected women may live with and attach meaning to their breast cancer risk changed as I accessed their worlds through their stories.

Ethical Considerations

The proposed study received ethics approval from the Health Research Ethics Board at the University of Alberta in May 2014. Operations approval to recruit for this study through the HBOC clinic was received in May 2014 through the Northern Alberta Clinical Trials and Research Centre (NACTRC) in Alberta. Several ethical issues were considered in the design of this study. The ethical issues that I addressed were: (1) anonymity and confidentiality; (2) risks and benefits to participants; and (3) free and informed consent.

Anonymity and Confidentiality

To protect the anonymity of the participants, I disguised the identities of the participants by using pseudonyms in place of their names and altered or removed other identifiers in the document as necessary. The issue of confidentiality was honoured by arranging to have the

conversations held in either a private room at the University of Alberta, a participant's home, or a quiet public space as requested by the participant. As per the University of Alberta's mandate, all transcripts are being kept in a locked and secure location for 5 years, and will be destroyed after this time period has elapsed.

Risks and Benefits to Participants

During the conversations, participants may become emotional when revisiting experiences related to their increased risk for breast cancer. During the first conversation, I provided each participant with a business card for the HBOC team psychologist. I advised participants to either contact the psychologist and/or their family doctor if they wished to receive counsel about the emotional upheaval that may surface during and/or after the conversations. I also offered to reschedule sessions or redirect the conversation if the participant felt that she did not want to talk about an experience that was too emotionally disturbing. In honour of the participants' time and commitment to the study, I provided, as necessary, participants with funds to cover parking, mileage, and child care costs. None of the participants required child care. Conversational interviews were conducted at the University with two of the participants. I reimbursed them with a cheque to cover their mileage to and from the University at $0.48 per kilometer and paid for their parking expenses.

Additionally, each participant received a gift certificate for $25 dollars for bath/shower and hair products at the end of our first conversation as a way to show value for their time and thank them for their participation. Although there was no direct benefit to the women for participating in this study, several participants thanked me for listening to their story and some of the participants expressed that talking about how they live with risk for HBC was cathartic.

Informed Consent

I read aloud with each participant the information letter about the study and the consent form before the commencement of the first conversation (see Appendix D and Appendix E). A digital recording of the conversations began after receiving written consent before the first conversation and verbal consent to proceed during subsequent conversations.

Dissemination

The dissemination of findings from the proposed study will be taken to the public domain in the following ways: (1) submission of an article to a peer reviewed journal; (2) submission of a summary of findings to the Genetics Clinic, HBOC Society, and the HBOC Clinic; and (3) provision of an oral presentation at the 2015 International Society for Nursing in Cancer Care conference.

CHAPTER 4 – THE FINDINGS

I begin this chapter with brief individual narratives to provide context for each participant. I then present thematized experiential descriptions within the life existentials: lived space, lived body, lived time, and lived relations to reveal interpretive insights about how living with risk for HBC is experienced through these life existentials. At the end of this chapter, I discuss the essences. In this chapter, phrases and words in italics (without a reference) are the words of the participants. Although the words of the participants are verbatim, repetitive phrases and filler words such as: um, you know, and like etc… have been removed for ease of reading.

Introduction of Participants

I met with nine unaffected women (those with no personal history of breast and/or ovarian cancer), living in families where a BRCA1/2 genetic mutation could not be identified, to explore how they experience living with risk for hereditary breast cancer (HBC). All of the women in the present study were being followed bi-annually at an HBOC clinic and had a projected lifetime risk of at least 20% for HBC. Four of the women were between 25 and 35 years of age, three were in their early forties, one was in her mid-forties, and one was in her late fifties. Five of the women were married, two were living with their partners, one was in a long-term relationship, and one was single. Four of the women had children. Two sister dyads from two families participated in this study. The mothers of all of the women had been diagnosed with breast cancer and three of the mothers were deceased. Although the focus of this research was to explore how women live with risk for HBC, four of the women (two sister dyads from two families) had a familial history of ovarian as well as breast cancer. Therefore, in the findings, some of the women discussed experiences related to ovarian as well as breast cancer in the family.

Marie

Now in her mid-forties, Marie has lived with the knowledge that she is at-risk for HBC for many years. Although all but one of her female relatives was diagnosed with cancer before the age of 40, the gravity of her family's cancer history did not really sink in until her mother was diagnosed with breast cancer when Marie was 14 years old. Then, when Marie was 29 years old, following her mother's breast cancer reoccurrence and death, the realization that she could follow in her mother's footsteps led Marie to ask her family physician to refer her for yearly mammograms. Marie recalled:

> *I'd had both my kids and my mom passed away, all in a 24 month frame and I was a wreck…I remember going in to him and saying – Okay, like enough is enough now and I want to do this.*

The response her family physician gave her was that *they don't do screenings for 29 year old women…maybe when you're 35.* Given that Marie's mother was diagnosed with breast cancer at 36 years of age, she went to her obstetrician for a second opinion. After going through her family's cancer history, her obstetrician agreed that she should be screened and referred her for her first mammogram. Even though Marie was referred by a physician for mammogram screening, as she moved to different cities and provinces (due to her ex-husband's work) she often found herself feeling out of place as staff at different screening clinics questioned her presence.

> *In some of the mammogram clinics because I wasn't diagnosed, because I was under 40 years old, it almost was they were like, [Sigh], really? Like why are you doing this?*

In her thirties, a referral to the HBOC clinic in Alberta was the start of a long and supportive relationship between Marie and the healthcare professionals at the clinic. For Marie, the care that she receives at this clinic has helped her to become *more relaxed and much more focussed on living my life and not worrying about cancer.*

Pam

Pam is in her late twenties and lives with her partner a little more than 2 hours outside of Edmonton. Pam started to become aware of her family's cancer history around the age of 10 when her mother was diagnosed with breast cancer. Her mother had a double mastectomy at 45 years of age and has been living cancer-free ever since. Even though it was scary for Pam to learn that her mother had cancer, an awareness and concern for her own personal risk for HBC did not come to the forefront until she sought medical attention in her early twenties for health issues unrelated to the breast. At this point in her life, as she moved to different provinces for her studies and had to repeat her family's cancer history to different doctors, she was surprised and frustrated to hear some of the doctors say that her concern about her breast health was *not a big deal* – to *wait until you're 30* for mammograms. Then, about two years ago, when she moved to a rural town in Alberta, a conversation she initiated with her new doctor about the possibility of a prophylactic mastectomy led to a referral to the HBOC clinic.

Morgan

As a child, Morgan learned from her parents of the seriousness of breast and ovarian cancer when her mother and then her grand-mother were diagnosed. Although her mother is a breast cancer survivor, her grand-mother succumbed to ovarian cancer. For Morgan, the gravity of her personal risk for HBC was not understood until she started going to the HBOC clinic in her mid-twenties. Now in her early thirties, Morgan was experiencing several positive changes in her life at the time of this study. Shortly after we met, she got married. Then later in the fall she started a new job while continuing to work on her graduate studies. However, amidst all of these positive changes, there was a tension and sadness that filled the air as she told me that her aunt's ovarian cancer had spread earlier in the year and that her time was now very limited. Between our first and second conversations, her aunt died.

Adele

Adele met with me after her very first appointment at the HBOC clinic. Now in her mid-twenties, Adele followed in her sister Morgan's footsteps and started screening at the clinic as soon as she was old enough. Adele seemed to be older than her years as she recalled the experience she had caring for a close family member who was being treated for cancer. Shortly before her aunt was diagnosed with ovarian cancer, Adele had accepted a teaching job near her aunt's home. Since the job was far from Adele's home, it made sense to live with her aunt while teaching. But, within that year her aunt became unwell and found out she had cancer. Adele immediately helped out more with her aunt's young family and cared for her aunt. Learning of her aunt's terminal diagnosis (due to the spread of the ovarian cancer) earlier this year was very difficult for Adele for she thought of her aunt as a second mother. Between our first and second conversations Adele's aunt had died. Although I met Adele at a very sad time, I was amazed at how she continued to see the positives in her life and the hope that she carried for herself and others in her family.

Lucia

Just before I met Lucia at the HBOC clinic, the RN coordinator alerted me to the death of Lucia's mother from breast cancer about six months prior to our first introduction. I remember walking to the exam room and thinking how hard it would be to talk about what it is like to live with risk for HBC so soon after her mother died. After providing her with more information about the study, Lucia told me that she would like to participate. In her mind, she figured that it did not matter if she talked about it today or 5 years from now – her feelings would still be raw. For many years, Lucia had coped with screening for herself while caring for her mother and father while they were being treated for cancer. Lucia recalled a time when she was visiting her

mother, father, and two uncles at a cancer hospital when all four of them were either being treated or checked for cancer. When I met Lucia, now in her early 40s, both of her parents and one of the two uncles were deceased.

Wendy

An awareness of hereditary risk for breast cancer started to form when Wendy was in her late teens around the time her mother was first diagnosed with breast cancer. Her mother had a reoccurrence and is currently living cancer-free. Now in her early forties, Wendy has spent much of her life paying particular attention to her health. Not knowing what is causing many cancers in her family has led Wendy to question the role of the environment, stress, and lifestyle in the development of cancer. Her search for answers motivated her to make certain lifestyle changes in the hope of preventing and/or lessening her risk for cancer. Along with these changes, living with risk for HBC has instilled in Wendy a great desire to enjoy and live her life to the fullest.

Genevieve

I met Genevieve and her sister Tabatha at the HBOC clinic at the same time. Genevieve was in her early 40s and has three young children. For Genevieve, an awareness of there being hereditary risk for breast cancer in her family began about 11 years ago when her mother was diagnosed with breast cancer. At this point in time, Genevieve was busy starting a family. Then about 4 years ago, a benign lump in her breast caused her to identify more with her mother as she said: *I feel like it's just, it's going to happen because I have the same breasts as my mom*. Although Genevieve had undergone regular mammogram screening for several years in another province, when she moved to this province in her late thirties and showed her new doctor the letter from the geneticist and told him her family history as well as her history of a benign lump, she was surprised to hear him say that *he did not believe in getting tested until you're well into*

your 40s. This event led Genevieve to ask to be followed at the HBOC clinic. For Genevieve, the support and expert advice she receives at the HBOC clinic eases her worries about her risk.

Tabatha

When I met Tabatha, she had just finished her first appointment with one of the doctors at the HBOC clinic. Tabatha's mother was diagnosed with breast cancer when Tabatha was in her mid-twenties. After receiving a letter from a geneticist with recommendations for regular screening, Tabatha went to her family physician to request yearly mammograms. As Tabatha moved from one place to the other, she found that while some of the physicians took the letter seriously others dismissed the recommendation. Even when she was referred to a mammogram clinic, Tabatha found that between 25 and 30 years of age, she would sometimes encounter resistance from technicians and felt like she was *wasting peoples' time* when she recalled: *I'd go for mammograms and the ladies would be like, you're too young to be here for mammograms.* Now in her mid-thirties, she decided to join her sister Genevieve and be followed at the clinic. For Tabatha, being armed with the knowledge that is available about cancer, having her breast health monitored, and receiving support from her family and the healthcare professionals at the HBOC clinic gives her hope and has made the possibility of developing cancer *less scary*.

Misty

When I met Misty at the HBOC clinic she was quite relaxed and happy to share her story. Misty comes from a very large family. Given that she has five sisters and five brothers, her mother's death from breast cancer did not signify for Misty a hereditary link. One by one, as three of her sisters were diagnosed with breast cancer, the thought that these cancers could be hereditary became more plausible. While in her late thirties, Misty recalled the geneticist sitting down with several family members to explain that even though a known mutation had not been

found, there was a *very good possibility that we have hereditary breast cancer in the family.* However, this was not the beginning of regular screening for Misty. When Misty was in her early twenties her doctor decided to send her for yearly mammograms at the hospital after learning of her mother's breast cancer diagnosis. Now in her late fifties, Misty has been followed by one doctor in particular at the HBOC clinic for more than a decade.

Understanding Risk for HBC through the Life Existentials

Lived Space

At first glance, we might think of the experience of space as concrete – the physical environment in which we dwell. Although our physical space can affect how we feel about a phenomenon that we are encountering (whether it be an object, person, or thought), there are many abstract spaces we move in and out of depending on what we are thinking about, changes in our emotions and moods, the roles we assume, and the relationships with others that we experience in our everyday lives (Austin, Brintnell, Goble, Kagan, Kreitzer, et al. 2013).

van Manen (1990) describes lived space in relation to how the space we occupy makes us feel. To use a simple example, when I ride the bus to school in the morning I usually listen to music on my headphones. Listening to one of my favourite songs transports me to far-away places where anything is possible in my imagination. The boredom I felt earlier as I watched cars cruise along beside the bus from a crammed view point vanishes as I don my headphones. This simple example shows how a technology that emits music into my ears can change my mood and move me into a different space.

Although there are many spaces that we move in and out of depending on various factors such as our roles, emotions, relations with others etc… the stories that the participants told in relation to living with risk for HBC revealed a shifting in and out of a normal life space and a

dark space where they contemplated their risk. Certain events/triggers move them into a dark space where they become uneasy and anxious about the risk they carry. I begin this discussion about the normal life space they occupy most of the time – with risk for HBC in the background – and then show the dark spaces they move into when they become anxious and/or fearful about their risk.

Just Moving Along: Living a Normal Life

All of the women talked about how most of the time they simply *move along* in their everyday lives with the knowledge of their risk for HBC in the background. In this space, Marie feels *content to just kind of go through life and not think about it and not worry about it.* Despite their risk, these women live full lives, achieving their life and career goals and enjoying what life has to offer. For example, while Pam gets on with her life as a school counselor and entertains the thought of becoming a registered psychologist, Morgan is finishing up her graduate studies program in social work. Regular day-to-day life is described by Lucia as getting the *kids off to school…suppers and work…you know, regular stuff.* Whereas, for Pam part of living a normal life is not following or being overwhelmed by the latest health claims or fads to prevent cancer. Thus far, she has not been advised by her doctors

> *to do anything specific… so, I'm not eating any more blueberries, cutting out alcohol completely, or stopping my birth control pill…I'm trying to live a normal life because I don't know if this is actually gonna happen for me or not.*

On the surface, the way these women conduct their lives appears to be in line with what many people in society strive for. However, a closer look into the lives of these women reveals how the risk for HBC that they live with in the background sometimes comes to the foreground and moves them into a dark and fearful space. Certain events act as triggers that move these women out of the everydayness of life and into a dark space where they confront their mortality.

Moving into those Dark Spaces

There are certain events that temporarily shift these women out from their everyday lives and into a dark space. In this space, fear and/or anxiety about the potentiality of being next in the family to be diagnosed with breast or ovarian cancer permeate their thoughts. As several women talked about the dark spaces they enter into to ruminate over their risk and imagine what could happen, they used metaphors such as Russian roulette and ticking time bomb to describe what it felt like to dwell in this space. For example, Pam uses the Russian roulette metaphor to describe how she feels when she enters those *dark places* as she waits for her screening results in the waiting room at the HBOC clinic. Russian roulette refers to a dangerous game where it is not known whether the firing of the next bullet will be a real bullet or a blank (Russian roulette, n.d.). Although 90% of the time Pam is not thinking about her risk, it is during a screening appointment that she finds herself wondering:

> *is this going to be the time that it maybe won't come back okay, sort of like that Russian Roulette thing… I dodged the bullet last time, things were good. Another round in the chamber, is it going to come back good again?*

Living like a *ticking time bomb* is a metaphor that was used by Marie, Lucia, and Adele to describe what it feels like to live with risk for HBC. The term ticking time bomb is defined as a situation that will likely result in a harmful outcome (Time bomb, n.d). For Marie, even though she did not see her risk *as a huge negative anymore I still look at it like a time bomb. I still firmly believe somewhere in my mind there's a good chance* (of being diagnosed with breast cancer). Although Marie likened living with risk to living with a *ticking time bomb,* she stated that *there is a bit of hope* in that *maybe it will never happen and it will just keep ticking.*

An event such as the discovery of a benign lump in the breast was recalled by several women as an experience that moved them into a dark space where the fear that they had imagined in relation to their risk before the discovery became more real. For example, Morgan

recalled a moment in time when the discovery of a benign lump in her breast changed the way she experienced fear in relation to her risk for HBC. Although Morgan identified herself as a worrier by nature, up to the day a lump was found, she recalled not having *too much fear about the appointments.*

> *I had just went and it was just for a physical appointment, that she was just going to check me and then I would have my MRI a month later and I'd be good to go. So she found a lump and that was, like, just devastating because we were going to our appointment, my mom, sister and I, and then after that we were going to the hospital to visit my aunt, where they had just found out that her ovarian cancer had spread…That whole day I was just walking around in a daze. I was just stunned that that had actually happened…The doctor said it's probably nothing, and I said but you know, like my thought is it's probably nothing, but you're sending me today, so that scares me.*

Morgan recalled a *different kind of fear* that took hold of her after the lump was found. Prior to that moment, Morgan's fear about her hereditary risk was mitigated by her age. When Morgan went to a screening clinic in her mid-twenties, she noticed that other women in the room were much older than her.

> *Part of seeing the other people around me made me feel like it probably won't happen to me. I'm still pretty young, like only 25.*

Now at the age of 30, even though she remembers being advised that the lump was a fatty deposit, the idea that something had changed in the composition of her breast tissue seems to have shaken her. The expectation she had of undergoing screening tests and hearing the doctor say that she is *good to go* did not happen on that day.

Genevieve recalled an experience about 4 years ago when a lump was discovered in one of her breasts during a routine exam. Although her mother's earlier breast cancer diagnosis was the first time Genevieve started to think about her own risk, these thoughts were swept to the back of her mind as she cared for her young children. The day the lump was found was *scary* - causing her to go into *panic mode.*

> *It ended up being just a benign, just a cyst or something like that in the breast. So that was good, but then it started making me really think about it a lot more, just had a lot more conversations with mom and this is going to sound strange, but I feel like it's just, it's going to happen because I have the same breasts as my mom. My mom has excess breast tissue under her armpit and that's where one of her cancers was found and I am the one that has the excess breast tissue, same side…*

Within Genevieve's experience of discovering a lump, the similarity she shared with her mother in relation to the shape of her breasts and excess breast tissue under her armpit made the threat of following her mother's footsteps seem more plausible.

Wendy was attending a conference for her job in the city when she received a telephone call from the screening clinic about a suspicious finding in one of her breasts.

> *I went to a conference and my cell phone rang and it was a weird number, so I just answered it right in the middle of this conference and she was straight up with me and all of a sudden a tear starts trickling down my face and I got up and left… she said that they'd found a lump in the MRI and yeah, I'll never forget that, standing in the hallway and these tears coming down and just thinking…F.*

A few days later Wendy underwent a biopsy that turned out to be benign. About two weeks passed between the biopsy and receiving her results. What made Wendy's experience quite different from the other women was her belief that she would not undergo any treatments including surgery if cancer was found. This belief formed as she experienced cancer through her mother's diagnoses and treatments. During the two week waiting period between the time of the biopsy and disclosure of Wendy's results, she recalled lying awake at night, crying as she wondered – *what am I going to do? What do I have to get in order? How long do I have?*

Outside of the discovery of a lump in their own breasts, several women expressed how exposure to cancer in other family members/friends, moved them into a dark space where they became anxious about the possibility of being diagnosed with cancer. At the time of this study, the sisters – Morgan and Adele – experienced a death in the family. Their aunt was terminally ill

with ovarian cancer when we first spoke and died between our first and second conversations. Morgan recalled:

> *In the last month my aunt has been dying and for [sister] and we really struggle with that because it's right in front of me. It's right in front of my face and I think about it and I like to believe that there's something else, a higher power, but when I see someone like that, it takes away my hope, you know? If it got her, what's going to stop it from coming to me or coming to [sister]?*

Adele also found herself questioning in her mind if she would have the same fate as she watched her aunt's health deteriorate.

> *In the back of my mind it was always like a tap, tap, tap creeping in, like this could be me, you know? And I never wanted to bring it about me, I just wanted to focus on her, but it was always in the back of my mind.*

The past year has been difficult emotionally for Adele as she coped with not only her aunt's terminal cancer diagnosis, but the breast cancer diagnosis and death of the mother of one of her students. Throughout these experiences Adele found herself wondering if one day she would leave a child behind as she recalled:

> *There was a little girl in my class and her mom had breast cancer and passed away of it. So it was, like, I was going to this funeral of this little girl that her mom passed away [getting emotional] but, and then my aunt's got radiation she's finishing, you know? So it was like, you know, two things, and then right after that, they had found out it would probably just be [getting emotional] a few more months for my aunt…so when the mom of the little girl in my class passed on, I was thinking - am I going to have a daughter that I'm going to leave? That's where my mind goes because I'm worried about it all the time.*

For Genevieve, there have been times when hearing her friends say they wished their moms were still alive to experience certain life events led her to imagine *that could be me* as she reminded herself that her risk was *higher than most.* As she moved into this space she ruminated about the *potential loss* – of not being there for her young daughter and sons.

For Marie, there are times when triggers such as an exposure to cancer in the family will spark a fear that leaves her thinking that she *would literally go once a month for a mammogram*

if they'd let me. For example, Marie remembered nursing her brother's second wife, who died from stomach cancer, and suddenly *thinking, I need to go have a mammogram.*

The preceding stories reveal how knowledge of risk, an awareness of cancer in others, and the breast cancer technology we have today move some of the participants into a dark space where they experience fear and/or anxiety about their risk for HBC. If we are to believe as Aristotle (2000) did that "death is the most fearful thing of all" (p. 49, III5b) then disease is the image of fear (Fisher, 2002). The fear that the participants in this study experience is tied to a threat to their mortality and therefore stands "as surrogate for having an experience per se" (Fisher, 2002, p. 117). Although breast cancer technology is liberating in that it provides women with an opportunity to monitor their breast health and hopefully detect cancer at an early stage, there is more to the redemptive nature of technology that we need to consider. As Heidegger (1977) wrote, technology should not be considered to be neutral for it has the capacity to challenge and reveal what is before us in ways that change the way we know of and think about the world (Schroeder & Conroy, 2015). Franklin (2004) expands this view and challenges us in her writings about technology to think of it as an entity and a practice. In her view, technology is multi-faceted in that it consists of a body of knowledge, organizes our way of being-in-the-world, impacts the way we relate to one another, and affects the way we experience space and time.

Lived Body

Phenomenologists believe that as human beings, we experience the world as embodied (van Manen, 1990). In his seminal work, the phenomenology of perception, Maurice Merleau-Ponty (1962) shows us how the world of things and others are understood through the lived body. The lived body is represented as the unity of the self and body; an embodied way of

being. As we go about our everyday lives, meanings are constituted from a constant dialogue between the self, body, and world. For example, as I approach a friend in a coffee shop I greet her with a wave and a smile to beckon her over to the table I am sitting at. As she talks to me about what is happening in her life, I look her in the eye and lean in to not only show that I am listening and interested in what she is saying, but to narrow the space between us. In this relational space there is an ease and comfort that is felt between two friends. For the most part, my bodily existence is absent from my view. I experience the world as embodied. But what happens when there is a bodily disruption in this space? What if I had fallen moments before our encounter and felt excruciating pain in my knee? The harmony that I experienced between mind and body would be disrupted. In times of severe pain, Gadamer (1975) writes that the power of pain can be so strong that it can "cause us to withdraw from all external experience of the world and turn us back upon ourselves" (p. 75). In this sense the pain emanating from my knee would cause me to objectify my knee as I focus on it as a problem - restricting the way I relate to and understand the world.

In this study, a shifting between an embodied way of being and a disrupted sense of self and body was revealed during times when the women underwent screening procedures and times when the state of their health was under the gaze of others outside of the medical profession. They experienced the lived body as "the body knows" and "is there something wrong with me?"

The Body Knows

The recurrent ways in which some of the women experience anxiety through their bodies shortly before a screening appointment, reflects a bodily knowing. For example, the following story told by Marie reveals how she becomes more conscious of her body and prepares herself

both physically and emotionally for the possibility of finding a suspicious growth in her breasts shortly before and during a screening appointment.

> *It's usually about three or four days before my mammogram that I'll start sort of, okay, I have to go for a mammogram, and it's almost like I'm pep talking myself because I can feel my body getting tenser. I'll literally start doing breast self-exams twice a day prior to my mammogram. And I become a lot more body conscious before where I'm looking to see if there's changes. Do I see anything different, do I feel any different? I feel myself getting tense, I feel myself shutting down emotionally a little bit and then you know, I just become very logical. And everything sort of becomes about that one moment. So that the day of my mammogram… I have no emotion about it. I just shut down that part of it and I go through, this is what I have to do, this is what I have to pack for my lunch, this is the clothes I'm going to wear… everything's already planned out, and this is how I'm going to…and I'll even go so far as to go, okay, and if this time, it doesn't go as well, this is how I'm going to cope with that. This is where my emotional self is sitting, so that if this time you hear those words, this is how we'll deal with it today. And I am cold… I just…I shut down. I drive into the clinic and I sit there. I just sit. Sometimes I look through a magazine but I couldn't tell you what I read if you asked me two seconds later. I'm just there and it's just about the steps. This is the next step. Okay we're going to go do the films now, excellent. The films are good, excellent. Now I go to the doctor's office. And I don't think I even think about the magnitude of anything until I talk to the doctor, and then it's hearing that - "Okay, everything's good," and then all of a sudden it's like I check back in. It's not that there's never that fear. It's always there, it's just that I'm going to be on board to deal with it. I feel a huge emotional release* (refers to receiving a good result). *It is like - if you hold your breath for two minutes and everything is tense and you can feel every cell in your body screaming, and then it goes whoosh. When you take that first breath, that's how I feel. I end up with a headache usually the night of my mammogram, because I know that I've been so tense for the couple of days prior and it's just that release…My body finally starts to relax and I get a headache and my arms are sore.*

Even though Marie says that she holds a *glimmer of hope* each time she goes to the clinic, the description above reveals a temporary disruption in mind and body as she becomes more conscious of changes in her body while erecting a protective barrier through the tensing of her body and the shutting down of her emotions. After hearing that the results are clear her body relaxes as she looks to another six months where she will not *have to worry about that.*

For Misty, the way she experiences anxiety before a screening appointment has evolved over time. When Misty was in her 20s and 30s, she remembered feeling sick to her stomach about a week before a mammogram. It was an ineffable feeling that she could not describe to her

husband - *a horrible feeling that I'm next…that it's going to be me*. As Misty prepared for a screening appointment, she said that she experienced *dread* and said:

> *I can feel the start of the anxiety… the pounding heartbeats…and I know what it is and I just talk myself out of it*

Now in her late 50s, Misty found that the uneasiness she felt before an appointment lessened and usually occurred the night before. Part of the reason for less anxiety before an appointment came from the self-talk she engaged in while another reason was adding MRI screening to her monitoring. *That's how they caught another sister – was on an MRI* (referring to a breast cancer diagnosis). Even though Misty still experienced some anxiety the night before a screening appointment, once she was in the doctor's office and learned that her results were clear she said: *it's like I just want to do the jig, you know, I come out, oh, I got another six months, hey!*

Following the recent death of her mother, Lucia was surprised to find that she was not as anxious or emotional as she thought she would be during her last screening appointment. During past appointments, while she was caring for her mother and other close family members dealing with cancer, Lucia found herself becoming *emotional and panicky before the MRI*.

> *Inside the test itself, I started to panic. I could feel myself start to tear up and suck for air…I started thinking of my mom and what she went through – the appointments, surgeries, chemos – and I started thinking – what are they going to find? What is it? Is it this time?*

Given that Lucia was in the early phase of grieving for her mother at the time of this study, I wonder if the anxiety she experienced in the past in relation to her bi-annual screening appointments will lessen as she moves forward without the emotional heaviness and stress of caring for a family member with cancer.

As Morgan talked about the way she reacted physically and emotionally to an upcoming screening appointment, she used the metaphor – *cancer backpack* – to describe how her fears

about cancer were sometimes worn – becoming a part of her body. As I thought about this removable weight, I was reminded of a motivational speech by an actor in the movie *Up in the Air* (Reitman, 2009). In this movie, the lead character - Ryan Bingham – used the word "backpack" as a metaphor to illustrate the weight of the things we carry with us. He asked the audience members to pack their backpacks with all of the material stuff they have accumulated and try to walk while feeling the immense weight of these things through the straps of the backpack. Morgan carries a *cancer backpack* that she says is:

> *full of all of that crap and it's just heavy. I carry it around and every once in a while I can just put it to the side in the room and I can just be.*

The emotional weight of the cancer backpack appears to be heavy around the time that she is due for a bi-annual screening appointment. Even though she found that after an appointment there are

> *six months where I'm kind of free and clear…I plan this, I plan that…I'm always thinking about those appointments and I'm always thinking, what if? What if I just don't get, like you know, we have our Christmas vacation, but I have an appointment before. So that's where it's always on my mind and it's always coming up.*

For Morgan, about a week before a bi-annual appointment the worries that she experienced as she imagined *what could happen* took over her body and mind.

> *I still go to work and I'm still kind of moving through the motions and that sort of thing but I'm carrying it constantly* (referring to fear about HBC), *whereas most of the time I can kind of put it to the side, I'm not thinking about it as much…but when I have that appointment coming up the week before…at work I'm physically present but part of my mind is somewhere else, cause I'm worried about myself.*

Then on the actual day of the appointment, the worry and irritability that enveloped her for several days gave way *to a state of exhaustion by the time I'm there and I'm just there* that was followed by a state of relief when she received clear results.

In contrast, Tabatha recalled not feeling worried and/or fearful shortly before or during her breast cancer screening appointments. As she recalled these appointments she said:

I feel good about that, yeah. I mean, I want to stay on top of it, for sure, yeah. I have friends now that their mothers got, you know, cancer. More people I know have gotten cancer, mothers, people who are younger, so I definitely want to be on top of it if there's a higher risk. So yeah, I'm happy to do it. It's no skin off of my teeth to go in and go through a little discomfort to, in the end, find out whether I'm in good standing health-wise or not, so yeah… I don't really worry about it, no

For Tabatha, although she is happy to undergo bi-annual screening, living without a known genetic explanation for the cancers in her family causes some discomfort as she said:

Mystery is never great when it comes to health… while I'm happy I'm being monitored… if we have something really strange that they don't really know about, like some sort of weird, really strange genetic pop up, then that's a little…that's uncomfortable

Is there Something Wrong with Me?

For some of the women, there have been times when comments and advice from others made them feel unhealthy and/or times when they wondered if they were doing enough to prevent cancer. The reactions that Pam received in relation to her risk from non-medical people made her wonder about the state of her health. One experience in particular, being denied life insurance coverage in her twenties, made her feel like she was not healthy.

Probably the biggest headache for me with being high risk is you know, doctors on one hand are like, well you're high risk but you're fine but then there's these non-medical people that are like – Whoa- like, we can't even cover you life insurance wise because of this.

Additionally, there have been moments in her life when friends who know about her family's cancer history have cautioned her to *be careful, watch what I eat and keep going to those appointments.* Other moments such as a simple glance that revealed *worry* in the *eyes* of a friend or a comment made her question her present health. As Pam interpreted these passing glances and comments as a message that she was *unhealthy*, she questioned how it is that risk for a disease that may not occur labels her outside of the medical community as unhealthy. Similarly, Marie recalled times when friends and family members told her she *shouldn't eat that*

or she *should…blah blah blah.* For the most part Marie ignored the advice she received about what she could do to prevent cancer from friends/family members because it *almost adds an extra level of fear.*

Wendy was well aware of the mixed messages about cancer prevention she heard on television or the internet and has spent much of her life trying to figure out what she could do to prevent and/or lower her risk for HBC. As Wendy recalled what it was like to learn that a BRCA1/2 genetic mutation had not been found in the testing conducted for her mother and aunt, she remembered a conversation she had with a doctor. In this conversation, Wendy recalled how not knowing what it was that was being passed down in the family *amplified* the stress that she was feeling as she asked her doctor - *what's wrong with us? –why so rampant* (referring to cancer)? – *is it in our house*? – *is it something we do*? One of her doctors said to Wendy that *she thinks there is a hereditary gene out there that they haven't discovered yet and it's probably rampant in our family.* In the absence of a genetic explanation, Wendy searched for ways to reduce her risk. This search led her to focus on her body as she said:

> *I have gone to the extreme of spending probably over $20,000 on weight loss because I'm worried that weight is a factor and eating processed foods, so there are no processed foods in my house. I had the sleeve done. My stomach is half the size now. It was probably one of the best decisions I ever made.*

Besides changing her diet and maintaining a healthy weight, Wendy went to her doctor to address the stress she was experiencing and started taking *pills for stress.* However, despite the changes made to her lifestyle, for Wendy, there remains *the anxiety of what is wrong with me, what can I change?*

It appears that for some of the women in this study, the hereditary risk they carry is met with a perception among some non-medical family members and friends that they are not healthy and as such, need to optimize their health to reduce their risk. Not being perceived as healthy due

to risk for a disease may be played out in changes in the way insurance companies categorize those who are considered "normal healthy" and those who are at-risk for future disease. van Hoyweghen, Horstman and Schepers (2006) identified a change in the definition of health among insurers from a state that was viewed as "the absence of disease to a state defined as risk resistant" (p. 1229). Furthermore, the emergence of in-between health classifications that focus on health risks in disciplines such as public health, epidemiology, and prenatal care, have helped to change our definitions of health and disease. Along with the absence of disease, a definition of good health may now include the absence of risk for future disease. (van hoyweghen, Horstman & Schepers).

Lived Time

It is fascinating to think about the ways in which we experience lived time. For example, when I wait impatiently for my daughter to get out of the house and into the car, as I watch the clock in the car pass the time in which we should be leaving to get to an appointment I feel like time is running away from me. Whereas waiting for the results of a diagnostic test can make me feel like time is dragging me along an edge of uncertainty. The birth of my daughter was a marking of time where it felt like time stood still as I lost sight of everything around me and focused with intense joy on this new beginning. Although these experiences are lived against the background of measured time, we can see how lived time is not experienced objectively.

Additionally, lived time is more than our subjective experience of time. The temporal dimensions of lived time – past, present and future – is the "horizon for all understanding of Being and for any way of interpreting it" (Heidegger, 1962, p. 39). For example, how I carry myself today is connected to my past while my actions in the present move me toward who I am becoming (van Manen, 1990). The following descriptions from several women in this study

reveal how the temporal dimensions and the subjective experiences of time are experienced in relation to living with risk for HBC as "markings in time, "living in the moment" and "indecision within the extended future."

Markings in Time

Markings in time were described by some of the women as points in time that were associated with breast cancer in a close family member. As some of the participants get closer to the age in which their mothers were diagnosed with cancer, there is an anxiousness attached to these markings in time. For Pam, the hastening of time was felt as she got closer to the age when her grand-mother died from cancer and her mother was diagnosed with breast cancer.

> *The older I get the more I realize 47 is really young to die from cancer. You know, like my grand-mother did. I'm almost 30 now, I'm getting closer – it doesn't seem so old anymore – it doesn't seem so far away - so, it makes it more real, so the older I get, um, and the closer to the age I get – the more I think – like 45 is my scary age.*

When Genevieve recalled the time a benign lump was found in one of her breasts when she was in her late 30s, the fact that a lump was found close to the time when the doctors figured her mother's breast cancer was developing made her think that she was *on that ride we went through with my mom* (referring to her mother's breast cancer diagnosis and treatment).

For both Pam and Genevieve, cancer patterns in their families point to certain chronological ages that are marked with anxiety over the possibility of repeating their family`s cancer history. Through their experiences we can imagine time speeding up for Pam as she gets closer to the age in which her mother was diagnosed and her grand-mother died from cancer while for Genevieve there is an impression of time standing still as she makes a connection between the timing of the lump found in her breast and the estimated timing of the development of breast cancer in her mother. Reaching and surpassing certain milestone ages cancer-free can be monumental moments in time for these women.

For Marie, reaching and surpassing milestone ages challenged the cancer patterns she experienced through other family members and lessened the severity of the ups and downs of living with hereditary risk. Given that all but one female relative in her family was diagnosed with cancer before the age of 40, reaching and moving beyond this age cancer-free was an important and emotional turning point in her life.

> *When I got through my mammogram at 40, I burst into tears. Like, you know, a friend of mine bought me a dozen roses, it was a celebration, and the doctor even said Go buy a bottle of champagne, go celebrate… It was epic for me... I had made it to this unattainable number without being diagnosed.*
>
> *It's like a little victory… I feel like I won one for the team because I made 40, you know? And then I made 45… so every kind of little bit that goes by, I feel like I'm winning a little bit.*

This image of Marie, bursting into tears as she approached the age of 40 without a cancer diagnosis is powerful. It seems as though the age of 40 was a marking in time that was interpreted as an end point that few of her female relatives were able to surpass cancer-free. Like Morgan, Marie felt that fear related to her risk for HBC *was a constant thing that* she *carried* while in her thirties. However, surpassing the age of 40 cancer-free changed the way Marie moved forward and experienced life. Now, *the bricks* (referring to her fears) *aren't as big anymore.* For Marie, as she reached each birthday beyond 40 she celebrated it as an opportunity to *experience something else and something new.* Additionally, Marie moved forward in time with a different lens as she stated: *I don't see the world through negative eyes anymore.*

Living in the Moment

Living in the moment could be perceived as a life where a person attempts to be consciously aware of life as it is happening in the moment; a life where one's desires are sought out and experienced in the now. How and what we attempt to experience in life is unique to each individual. Several participants expressed how living with the knowledge that they are at-risk

for HBC moved them to reflect on what they wanted to experience, what was important in their lives, and to appreciate living life in the moment. For some of the participants, there was a sense of urgency to experience certain events in their lives whereas others felt a need to slow down to appreciate what life had to offer in the moment. For example, Marie spoke of the urgency she felt in her twenties to have certain experiences when her mother was coping with terminal breast cancer. *I was in a hurry to do everything and I was terrified… I wanted to get married, I wanted to have kids, I wanted to, you know, experience some things in life.* Marie *got married* and had her *kids* in a *very short succession* while her mother was ill.

Wendy recalled how living with risk for HBC fostered a sense of urgency in her to live her life to the fullest. The shift to make life more about experiencing new places and enjoying the moment with others rather than amassing material things arose around the time her mother was diagnosed a second time with breast cancer. Living with this risk drove her to accomplish as much as she could in a day, learn more about different topics through courses and to take more risks in life. For example, while Wendy was on vacation she tried recreational activities that she thought others might find scary – like *parasailing*. Wendy also recalled times, when she was sitting at her desk marking papers, she felt like she had *this little angel of death on my shoulder telling me – my time is limited so take stuff when you can.*

For some of the participants, living in the moment meant slowing down to appreciate and enjoy what was happening in the everydayness of life. Morgan expressed that learning to enjoy the moment and *to not worry about the small things* partly comes from her relationships with her mother and aunt. After experiencing what her aunt and mother went through with cancer, Morgan said: *you just appreciate what you have and you go forward*. *Just to be in the moment*

without the cancer backpack weighing her down redirected her focus away from the *stress of the what-ifs* to think about normal daily activities such as: *what are we going to do this weekend?*

For Pam, as she began screening at the HBOC clinic in her late twenties she started to think more about her mortality. Unlike some of the women in this study who felt some pressure to experience certain events in life sooner rather than later, Pam did not feel an urgency to get married, have children, or seek out new experiences. Instead, she found being followed at the clinic prompted her to live more in the moment as she said:

> *I think, more than I ever have before, about, I'm not invincible…one day something's going to happen and you know, if I were to get hit by a car this week, you know, what am I going to be upset about? And, you know, through that kind of thinking I have been much more in the moment… This is where I am right now and I like where I am right now.*

Indecision within the Extended Present

Several participants described the struggles they encountered when they contemplated in the present certain risk-reducing options in the absence of a known genetic mutation in the family. For example, as Genevieve recalled a time when she had a conversation with her doctor about a risk-reducing salpingo oophorectomy she said:

> *I don't know if I'm ready to full on address menopause, like I know I'm not planning on having any more kids, so it's not like I really need all those things anymore, but…I don't know...I know she told me* (referring to her doctor) *that that one* (referring to ovarian cancer) *is scary in a sense because it's hard to detect until it's almost too late…*

In her early thirties, it was easy for Genevieve to not make a decision about a risk reducing surgery because she was raising a young family and needed her breasts and ovaries. However, now in her early forties, she hesitates with this decision and states that although

> *it's something that is always in the back of my head* (referring to risk-reducing surgery options)*...I feel like I'm waiting for [sigh], I don't know - a sign. Like more obvious things to say, okay now it's time.*

As Morgan looks ahead, the pressure that she feels to have a risk-reducing salpingo oophorectomy in about 5 years from now yields mixed feelings. Morgan only has to look back in

time to the death of her maternal grand-mother and the recent death of her maternal aunt from ovarian cancer to understand how important this decision is for her. *When my aunt found out and she was ill, she said to my mom - Watch your girls and make sure that they have this.* Although Morgan felt she was blessed to have information about her risk and an opportunity to greatly reduce it by undergoing a risk-reducing salpingo oophorectomy, she sometimes struggled with how it may impact her life and how this surgery controlled the way she experienced time.

> *I mean it's easy to say - Yeah, well I'm going to get that hysterectomy at 35 - but it's not a simple procedure… I think about going through menopause at that age and loss of my bone density and everything - just trying to get that right cocktail of hormones… how it can change me so much and you know, are we done our family at that point? Well we have to be done and all of that, that it does, like it takes away. If I could eliminate that by knowing that yes, I do carry the gene or I don't carry, you know?...So I guess I'm still…I still think about that a lot because that's a decision that I'm going to have to face soon.*

Misty recalled having a conversation some time ago with her doctor about a prophylactic mastectomy and a chemo-prevention drug. The information she received from her doctor about these options surfaces now and again when she gets the feeling that she needs to decide to do something else outside of regular screening. However, there was a hesitation on her part given that her preference for a prophylactic mastectomy did not coincide with her husband's preference.

> *I don't know if I'd have the support at home…he (husband) would rather see me take Tamoxifen or the other, there's another drug and I'm just so not into drugs…That's probably what's sort of keeping me unsure of what to do, and then I think well, we have the MRI every year…I'm getting watched pretty closely.*

In addition to the conflicting views she has with her husband, the absence of a known genetic mutation in the family also plays a role in Misty's indecision as she said:

> *If I had a BRCA 1, there would be no decision. I would definitely have a double…but, I don't know if I do and I mean I don't know what we have but I know there's something…four in a family is too many.*

In contrast, as Pam came to understand how difficult it was for her mother to feel like she was a woman after living for twenty years with a double mastectomy, and how important it was for her to recently have reconstructive breast surgery, she started to wonder whether it would make sense for her to undergo a prophylactic mastectomy to avoid what her mother had gone through.

> *my mother survived breast cancer, but she had a double mastectomy and she had said, many, many times, "You know, had I known, I just would have cut them off and maybe this never would have happened… It reduces your chance by so much… I remember her saying that and that's kind of when the idea first went into my head that this is something I should be looking at and you know, the time that I chose to bring it up with my doctor was ironic timing because I'd spent four or five years like seriously thinking about it and doing some research and really looking at, you know, is this a smart decision for now or should I wait?*

In her late twenties, a conversation with her family physician about a prophylactic mastectomy resulted in a referral to the HBOC clinic. When Pam started going to the HBOC clinic she was surprised to hear one of the doctors say that a prophylactic mastectomy was not advisable.

> *I kind of thought that the doctors would be like yup – you're high risk – let's cut em off right? But to have them say: it comes with a lot of its own complications and there doesn't really seem to be anything wrong with you – like, you should probably wait and reconsider and for the past 2 years, that's sort of been the constant advice*

Although the advice she received from one of the doctors at the HBOC clinic was reassuring, after researching prophylactic mastectomies for several years and hearing about this risk-reducing surgery in the media, Pam struggled with the word – wait - as she pondered:

> *wait so we consistently see in these tests that you're okay – or wait until something happens before you seriously think about doing something like a prophylactic mastectomy. You know, it's a very um, that's a scary word – wait.*

The word – wait - originates from the thirteenth century Anglo and Old North French word – waitier. Its original meaning -"to watch with hostile intent, lie in wait for, and plot against" can be interpreted as an expectation for something negative or positive to happen (Wait, n.d.).As

Pam pondered how the meaning of the word "wait" can be positive or negative – depending on who is using it – she said:

> *When it's "wait" from a personal angle* (referring to a personal decision to wait), *I see it as a positive thing but when I hear "wait" from a medical professional, even though it's probably not intended that way, I take it negatively.*

For Genevieve, Misty, and Morgan, there was conflict and/or hesitation in relation to the timing of and/or the decision to undergo certain risk-reducing options in the absence of a known genetic mutation. For some of the participants part of their struggle with these decisions also stemmed from a reluctance to enter menopause prematurely, whereas one of the participants found herself struggling at times with a decision that was not supported by her spouse. Additionally, these women found it more difficult to make these decisions in the absence of a known genetic mutation in the family. In contrast, after doing her own research and reflecting on what her mother went through when she was diagnosed with breast cancer and had a double mastectomy, Pam seriously considered having a double mastectomy to hopefully avoid breast cancer. Only, the advice of her healthcare provider not to go ahead with a prophylactic mastectomy in her late twenties was surprising and a little bit scary for her as she wondered what they were waiting for.

The struggles that some of the women presented in relation to the risk-reducing options they contemplated in the present support the notion by Huijer (2005) that the knowledge we gain from predictive medicine can alter our concept of the future. Prior to the 1980s, the belief that breast cancer was a disease that just happened changed as epidemiological studies revealed a link between strong family breast cancer histories and a heightened risk for breast cancer (Anderson & Bandzioch, 1985; Ottman, King, Pike & Henderson, 1983). Today, as women contemplate what they can do today to reduce their risk in the future, one could say that the future has become as Nowotny (1994) called it – the extended present. Furthermore, Huijer (2005) suggests "the

future as an unknown, not-yet-existing time was abandoned and replaced by the future as an extension of the present" (p. 426).

Lived Relations

Our lived experiences are largely understood through our relations with others. Lived relations refer to that interpersonal space wherein aspects of the self are revealed to and concealed from the other. As van Manen (1990) writes, the relational space is a space where one can explore "how the self and the other are experienced" in relation to the phenomena under study. For example, when I go for my yearly check-up with my orthopedic surgeon, I step into a relational space where my aches and pains associated with arthritis and concerns about my diminishing abilities to function the way I am used to are taken in by my doctor as he stands silent before me with his arms by his side and his hands gently clasped in front of him. My doctor listens intently to what I am saying before he offers his thoughts in a non-hurried manner about what is going on in my body and what can or cannot be done. There is a connection between us that provides me with a sense that I am being cared-for.

Being cared-for is a concept that Noddings (2013) describes as a relation where the one being cared-for experiences a receptive presence by the carer that fosters a feeling of being accepted and supported rather than a feeling of being "held off or ignored" (p. 61). In the present study, the theme – "Being Cared-For" - emerged within the stories the participants told of their relations with certain healthcare providers. Another theme that emerged as I reflected on the relations the participants talked about with others outside of the medical community was – "Keeping Me Grounded". The proceeding stories these participants tell reveal how certain relational spaces these women enter in relation to their risk for HBC help them to cope with and/or come out of those dark spaces where they become fearful and/or anxious about their risk.

Being Cared-For

For all of the women in this study, even though most will attend a bi-annual screening appointment with trepidation, the reassurance they gain from receiving an all clear result (on the same day or a few days later, depending on the type of screening test) and the trusting relationship they have with the healthcare providers at the HBOC clinic far outweighs the fear/anxiety they temporarily experience. To illuminate how a caring relationship between participants and their healthcare providers can impact their relational space, descriptions of their experiences with healthcare providers within and outside of the clinic are provided.

For Marie, coming to the Breast centre, which later became the HBOC clinic, was *enlightening and refreshing.* There is a comfort for Marie in going to a place where she felt accepted. A place where she said: *I feel less like I have to advocate my position*. A safe place where she felt: *even if it does come back* (referring to the results) *that it's not good, they're going to understand where I'm coming from because there is more of a history there.* The caring relationship Marie experienced with the healthcare professionals at the HBOC clinic helped her to get on with living life as she said:

> *knowing that it's the same person looking at everything, that they're going to notice anomalies right away… usually within a couple of hours with the mammogram and within a couple of days with my MRI. It's changed my whole perspective. I don't walk around like this all the time,*(raising her shoulders up to her ears) *pent up and I am definitely much, much more relaxed and much more focussed on living my life.*

Contrastingly, Marie tells of an experience when she underwent a mammogram in another province and did not feel like the healthcare workers understood her fears about HBC.

> *I remember having my mammogram and them saying, "Okay, we'll call you," and literally throwing me out the door of the clinic and I sat in my car for 20 minutes and cried because I was devastated. You can't throw me out of the door and not tell me anything. What if I'm sick?...I was waiting for this horrible news because when you live like a time bomb, you don't ever think it's going to be okay. You're waiting for the worst-case scenario, and to have to wait three weeks like that is tough. It eats at you.*

Although Marie had gotten used to *being on pins and needles* as she waited three weeks for her mammogram results, she got to a point where she decided -

> *it didn't matter where I went in my life, I was coming back here* (referring to the HBOC clinic), *and I did. I came down here every year and had my mammogram done with the doctor. I was posted to (name of city) I flew back once a year.*

Looking back, as Pam remembered hearing other doctors recommend she wait until she was 30 or 40 to start mammogram screening, the anxiousness she felt back then about her risk is now tempered through the relations she has with the healthcare professionals at the HBOC clinic. For Pam:

> *Somebody following me that closely… it's a double-edged sword. I feel really reassured on one hand that somebody is following me in the sense that I feel like I'm being taken care of, that someone's looking out for me, that someone is making sure I'm okay, and that's really reassuring, and that's essentially what being followed means to me, but then there's that small part of me where I'm being followed for a reason and it's not a great reason.. So for the most part, I'm happy that somebody finally listened to me and referred me to the clinic.*

For Tabatha, living with what she called a *mystery gene* to potentially explain the cancers in her family and not knowing if she was carrying it left her feeling *a bit uncomfortable at times*. Being followed by experts at the HBOC clinic helped to diminish the discomfort she sometimes felt in relation to her risk for HBC as she said:

> *The comfort lies in the fact that there's some sort of knowing. People that know more than I would ever know about these things are watching me. But, when it's something that's a bit of a mystery it feels like a little bit more of a wild card. I still feel comforted going there* (referring to the HBOC clinic)

When Genevieve was 38 years old, despite the discovery of a benign lump in one of her breasts and a recommendation by her mother's geneticist to have yearly mammograms, her new family doctor denied her request for a yearly mammogram. At that moment, Genevieve decided to take her health into her own hands by calling the breast health clinic where her mother was being followed. For Genevieve, being followed by the healthcare professionals at the HBOC

clinic was both *calming* and *educational*. As Genevieve recalled conversations she had about her risk with the doctors she said:

> *They're definitely not scaring the crap out of me, she's just telling me stuff in very…and I think even when she's saying, "I'd like you to consider having your ovaries taken out," she's, you know, doing that with, if you're worried about this, then there's this, if you're worried about this, there's this. So, I think they're great. I mean it's rare, which is may be terrible, that you get that in a doctor all the time - who's willing to spend the time*

In the preceding stories, Pam, Marie, Tabatha and Genevieve experienced times, before they were followed at the HBOC clinic, when the concerns they raised about their family's cancer history and their risk were sometimes dismissed in the medical community. These experiences reveal an unequal power relation between some of the participants and prior healthcare providers who did not share in their concerns. It was as if they were outsiders looking in on a world where those who were either identified as BRCA mutation carriers or were cancer survivors were the only ones taken seriously. Instead of heeding the advice of some physicians to wait until they were older to start breast surveillance monitoring or internalizing remarks made by allied healthcare professionals that they should not be undergoing mammograms at their age, these women advocated for their breast health by seeking out other physicians and/or finding out if they could be followed at the HBOC clinic. This finding should make us pause to wonder whether these experiences are anomalies or more widespread than we think.

Keeping Me Grounded

Within the relational space, a supportive relationship with others can shape the way these women experience living with risk for HBC. The following stories reveal how supportive relations with others outside of the medical community impact the everyday lives of several participants in ways that help them to cope with risk and move out of or prevent them from shifting into those dark spaces where they start to feel fearful and/or anxious about their risk. For

example, when Morgan felt herself sinking into a space where she ruminated about her risk and the what-ifs, she found comfort in knowing that her husband was there to help her to move out of that space.

> *He listens to my concerns but doesn't let the concerns dominate us and that is what I need because sometimes I kind of get sucked into a black hole with this and I need someone to say, Okay… Just come back to where we are right now, And he does that for me, he grounds me that way.*

Open communication with her mother and sister about her worries and fears in relation to her risk also helped Morgan to recharge and move on with her life. Over the past year as Morgan witnessed the deterioration of her aunt`s health and subsequent death from ovarian cancer, she found herself feeling quite sad and low at times. The close and supportive relationship she had with her mother and sister helped her to move forward and make plans for her future.

> *Like my mom said, you know, with my aunt, I can't crawl into the grave with her… I just kind of have to plan for what I can plan for. And that's what I do, I just kind of go along.*

Similarly, Adele found the support she received from family and friends helped to lessen her worries about her risk for HBC. For example, the long walks and conversations she had with one of her friends helped her to release some of the worries and sadness she felt in relation to the cancer-deaths of her aunt and her student's mother.

> *Last winter was a really long winter and a lot of stuff happened, like the little girl's mom passed away in my class, my aunt had the tumours and then she had the radiation and I think I kept sane and her and I, we joke we have free therapy from each other because we can both unload and we joke that we leave it on the road.*

For Adele, her worries were also shared with her sister and husband. *With my sister, we go and we hash it out about the possibilities and the worry.* Even though she felt that she could talk more about her worries related to HBC risk with her mother and sister, the recent experience she had with her aunt's deteriorating health brought her worries to the forefront one night in a

conversation with her husband where he acknowledged her worries and expressed: *it's not like you're the only one in this, like I worry about you too.*

Some of the participants also talked about how the ways in which their mothers experienced and coped with a breast cancer diagnosis shaped their outlook on cancer. For example, Tabatha found the way her mother handled a personal breast cancer diagnosis and the way she lives her life now made the risk that she lives with *less scary*.

> *If something were to happen to one of us, we have this benchmark of somebody who survived and did a really good job of supporting other people*

Similarly, Adele identified some of her hopeful attitude about cancer with the way in which her mother lived her life after being diagnosed with cancer. Her mother had breast cancer when Adele was about three years old and is still living cancer-free today. For her mother, having cancer and being cancer-free for more than twenty years was like having a *second chance.* Adele recalled her mother often saying:

> *Make the most of life!" and she's always getting little things for us, always thinking of us. So my mom's very positive and very grateful. So yeah, it definitely rubs off.*

Although Pam feels the emotional support of her partner and mother, she tells of how the different ways in which her partner and mother worried about her risk for HBC affected her perception of risk.

> *This is our fifth province we've lived in together so we've gone through the process of finding some kind of health care professional many times together. So it's actually been him instead of my immediate family that has sort of been explaining to these people - "Cancer runs in her family - Her mother had cancer. But he doesn't approach it from the fearful sort of way as much as, like, this is a concern*
> *My mom's approach, because it's more fearful, I guess makes me worry about myself more. So it's a good balance because I do believe I need to have a small amount of worry. Otherwise I wouldn't have ended up in a situation where I am being followed at a high-risk clinic...*

For Pam, her partner's tempered concern for her risk counterbalanced the fear and worry that her mother expressed in relation to her daughter's risk.

Several participants also recalled how beneficial and comforting it was to have the support of a close family member when they underwent a screening appointment or when a lump was discovered in one of their breasts. One of the advantages of being followed at the HBOC clinic is the implementation of sister/family appointments. At this clinic, sisters and other family members being followed there are encouraged to book their appointments on the same day.

When I met Genevieve and Tabatha they had just started scheduling their appointments for the same day. Tabatha spoke of how comforting it was to have her sister there by her side during her first appointment at the HBOC clinic. When her mother was diagnosed with cancer, *they basically just said - You have cancer and then left her in the room and she had no idea and nobody to get her home.* Reflecting on her mother's experience gave Tabatha pause to consider how important it was to have her sister there to celebrate a clear result and to support her if *I leave knowing something negative*.

Although Morgan valued having her mother and sister by her side on the day of a screening appointment, she expressed mixed feelings about having her family with her when she thought about the reason for being there as she recalled:

> *within the last year it's been my mom and my sister and I and they schedule our appointments together and you know, at the clinic they'll say, "Well that's nice," and my sister says, "Well that's nice that we have each other," but I feel like, you know, yes it's nice and it's a great support and that day that I really needed them* (referring to the discovery of a lump)*, man, I wouldn't have wanted anyone else there, but on the other side I feel like it's just cruel torture because it's one thing to go through it yourself, but to see your sister sitting there is another thing, like just this odd, cruel, awful thing.*

There is a bitter sweetness to this gathering as Morgan reflected on the reason for being there and the helplessness she sometimes felt; knowing she cannot protect her younger sister from one day being diagnosed with cancer.

The connection Misty has with her sisters grew stronger with each experience of cancer in the family. *Were so much closer after we lost our first sister. Really brought us together, the rest of us, even as a family.* With this close connection they share with one another comes a commitment to ensure that when a sibling or niece was going to the HBOC clinic, *there's never one going alone, never.*

It was different for Lucia because she made the two hour drive to the HBOC clinic on her own. And yet, she felt the presence of her husband and two sons. The day before an appointment, they became *a little more huggy* and in tune with what could happen to Lucia.

> *Everybody's on the same time stop feeling. If my appointment's at 11 o'clock, my husband's on the phone by noon texting How are you? How'd it go? What's happening? And like I said before, with my kids and my parents and their health, there was no secrets. It was very open because you take the time you have and you value it. So they've grown up in that, so they know when I have an appointment, they're thinking too, "How's it going? What happened? What'd they say?"*

In the preceding stories, the relational spaces these participants experienced with healthcare professionals and others outside of the medical community revealed how important compassion and an openness to listen and provide support was to their well-being when they experienced uneasiness and/or fear about their risk.

Essences

In the previous section, thematization within the life existentials: lived space, lived body, lived time, and lived relations were used to offer interpretive insights and uncover the essences in relation to how these women live with risk for HBC. In a hermeneutic phenomenological inquiry, van Manen (1990) describes the essence of a phenomenon as "that what makes a thing what it is (and without which it could not be what it is)" (p. 177).

As I dwelled in the women's stories and reflected on the life existentials it became clear to me that the essence of the phenomenon I was studying, as van Manen (1990) explained, was not one dimensional – but multi-layered. Presenting their experiences within the life existentials deepens our understanding of how they live with this risk. However, when I looked at the whole and the parts of their stories I saw a moving in and out of a fearful space where they imagined the what-ifs in relation to their risk for HBC as an overarching essence that interconnected with the ways in which they experienced lived time, lived body and lived relations.

Moving In and Out of the What-Ifs

In the present study the participants described living in a normal space as a space they dwelled in most of the time. They also described moving in and out of a what- if space where participants temporarily felt anxiety and fear as they faced their mortality. Moving into the what-if space was triggered by certain events, such as exposure to cancer in other family members, a screening appointment, the discovery of a lump, and/or reaching certain ages attached to a cancer diagnosis in close family members. As some of the participants moved into this what- if space, they became more aware of their bodies, particularly their breasts as they looked for changes and braced themselves for the possibility of being diagnosed with cancer.

Moving into this what- if space also brought concern for future possibilities and changed the way time was felt. For example, time was felt by some of the participants as hurried as they felt an urgency to have children before deciding on a risk-reducing surgery. Time was also felt by some of the participants as slowed down as they consciously tried to live life more in the moment. In contrast, the potential for a breast cancer diagnosis in the future led one participant to see time as potentially limiting – prompting her to focus on living life to the fullest in the moment.

Coping with and/or moving out of these what-if spaces into their normal space was aided by the support these participants received from family members, friends, and healthcare professionals. Additionally, for some of the participants, experiencing how close family members coped with a personal cancer diagnosis and how they lived their lives today helped to shape their outlook on cancer. For example, the positive and hopeful attitudes that two of the participants expressed when looking at their future appeared to be tied to the knowledge they had about cancer, the cared-for feeling they experienced when being watched closely by healthcare professionals, and the supportive relations they had with close family members and friends. Therefore, it appears that the tension that some of the participants experienced as they approached a clinic appointment time was eased and/or made more livable through the care they received at the clinic and the support they received from family members and friends.

Thus, I see the shifting in and out of the what-if spaces as a part of their life journey where the potentiality for cancer follows them much like a shadow that at times is hidden from view while at other times permeates the senses. These participants continue to adjust to the shadow that often lingers in the background – cognizant of their risk for HBC as they forge

ahead and experience the joys and hope that fills their lives. On this note, I close this chapter with an adapted poem called Shadow by breast cancer survivor, Karen Scott Barss (1999).

Shadow

I have this lingering shadow
That now comes along with me;
It's an escort on my journey;
That's how it's going to be.

There's no use in pretending
That it just isn't there;
Its looming greyness grips me
In worry and despair.

At times, I find contentment
With this new, unwelcome friend
If I accept its presence
And face the sun ahead.

Karen Scott Barss

CHAPTER 5: DISCUSSION

The purpose of this research project was to explore and gain an in-depth understanding of how unaffected women (those with no personal history of breast and/or ovarian cancer), living within families where a BRCA1/2 genetic mutation was not found, experienced living with risk for hereditary breast cancer (HBC). van Manen's (1990) Hermeneutic Phenomenological approach was used to gain access into the worlds of these women and to give voice to their lived experiences. The findings in the present study add insights into the ways in which a specific group of unaffected women live with a technology that on the one hand offers comfort in knowing that they are cancer-free in the present and on the other hand temporarily invokes fear and/or anxiety about the possibility of being next in the family to have cancer. Recall that the term ``technology`` was defined in this study as both an entity and a practice that consists of a body of knowledge and a way of organizing our way of being-in-the-world and impacts the way we relate to others (Franklin, 2004). In this chapter, I discuss and relate the findings to relevant literature and then discuss the study limitations.

Moving In and Out of the What-Ifs

Moving in and out of the what-ifs emerged as an overarching multi-layered essence. This essence was embedded in the ways in which the participants experienced lived space, time, body, and relations. Although previous research in this population of women has provided valuable insights about how familial experiences with cancer may impact the forming of a woman's sense of self, perception of cancer risk, engagement in self-care strategies, and how certain events/life stages trigger fear/anxiety in relation to the possibility of developing breast cancer, none of the studies referred to the shifting in and out of the what-if spaces as a theme (Underhill, et al. 2012; Appleton, et al. 2000; Kenen, et al. 2003a; Kenen, et al. 2003b).

In the present study, movement into a what-if space was referred to by the participants as a dark space where they ruminated over their risk and contemplated what could happen. Although all of the participants expressed that most of the time they did not dwell in this dark space, insights gleaned from this study provide us with an in-depth understanding of how these what-if spaces temporarily invoked anxiety and/or fear in relation to their risk for HBC, how they coped with the what-ifs and what helped them to move out of this space and back into a normal life space where they got on with their lives with their risk in the background.

Just Moving Along: Living a Normal Life

Living in a normal life space was described by the participants in the present study as an everyday living space where they found themselves most of the time tending to everyday routines – which could entail getting on with their careers, studying, caring for children, planning for vacations etc… with knowledge of their risk in the background. Previous research revealed how important it is for women to consciously try to get on with living their lives without having the worry they carry about their risk for hereditary breast and/or ovarian cancer (HBOC) take over their lives (Appleton, et al. 2000). Several participants in the present study spoke of how they consciously tried to remove the fear and worries they carried about their risk in order to live a normal life where they could be themselves without having their risk take over their sense of self.

Moving Into the Dark What-If Spaces

In the present study, certain events and markings in time such as: a breast cancer screening appointment, the discovery of a suspicious lump, media reports about breast cancer, experiencing cancer through a diagnosis in family members and/or others, hearing others talk about cancer, and reaching certain ages at which a relative was diagnosed with cancer were

triggers that moved them out of their normal everyday life space and into a dark space where they worried and/or became anxious about the what-ifs. These triggers were identified in previous research on the experiences of unaffected women living with and without a BRCA mutation as events that aroused worry and/or anxiety about their breast cancer risk (Underhill et al., 2012; Appleton, et al., 2000; Underhill & Dickerson, 2011; Werner-Lin, 2007).

The present study adds to our understanding of how surpassing certain ages in which close relatives were diagnosed with breast cancer can impact more than a woman's anxiety levels. Similar to previous research by Appleton et al. (2000), one woman in the present study expressed a decrease in her anxiety levels as she surpassed certain ages linked to a breast cancer diagnosis in her relatives. However, passing this specific marking in time resulted in more than a lessening of her emotional ups and downs related to her breast cancer risk. For this woman it was an epic turning point in her life that was to be celebrated. It was a point in time that helped her to move out of a negative space and into a positive and more hopeful space.

Additionally, whereas previous research points to the surveillance appointment as a moment in time when women become more body conscious and anxious about their risk for HBOC (Underhill & Dickerson, 2011; Underhill et al., 2012; Appleton et al., 2000), the experiential descriptions many women presented in the current study evoked compelling images that revealed a back and forth movement between an embodied relation to being-in-the-world and a temporarily disrupted sense of self and body. For example, as some of the women got closer to a screening appointment, not only did they check their bodies for changes, they also described bodily reactions such as: feeling sick to their stomachs, having migraines, panic attacks, sore muscles from being tense before receiving their results, and/or feeling totally exhausted emotionally by the time they got to the clinic. These intense feelings were met with

great relief each time they heard that their screening results were clear. In a sense, hearing the results marked a moment in time when they could check back into their normal everyday lives.

Outside of breast cancer screening, some women at high risk for HBOC may be asked to consider having their breasts and/or ovaries removed to greatly reduce their risk. We know from previous research on women who are carriers of a known harmful BRCA mutation that undergoing a risk-reducing surgery can result in a feeling of being more in control of one's health (Dagan & Goldblatt, 2009). In the present study, there was a feeling of hesitation among some of the participants as they talked about how difficult it was for them to consider a risk-reducing surgery option. Some of the participants remarked that knowing if they were carriers of a known BRCA genetic mutation would help them to make a decision. Wanting validation of one's risk through BRCA genetic testing was also found in a study by Kenen et al. (2003b) to be an important part of the decision process among a group of unaffected women who were considering prophylactic surgeries.

Additionally, for some of the participants in the present study who were considering a risk-reducing salpingo oophorectomy, there was a hurried feeling to get on with starting a family sooner rather than later. Prior research on the experiences of women identified as BRCA mutation carriers also revealed an urgency to start a family after learning of their mutation status (Werner-Lin, 2008; Hamilton & Hurley, 2010). The preceding discussion presents instances where the participants moved into a what-if space to contemplate their risk, what could happen, and options they could consider to reduce their risk. The findings also revealed insights about what helped these participants move out of the what-ifs and back into a normal life space.

Moving Out of the What-Ifs

In the present study, relations between the participants and their healthcare providers as well as the support of family members and friends helped them to cope with and move out of those dark spaces where they temporarily became anxious or fearful about what could happen. A feeling of being reassured that they could find cancer early on and be updated with current knowledge by experts at the HBOC clinic as well as a connection with the experts was very important to the women in the present study and is consistent with previous research (Appleton et al. 2000; Parsons et al. 2000; Underhill & Dickerson, 2011; Underhill et al. 2012). However, the present study adds to our understanding of what it means for unaffected women living in families in the absence of a known genetic mutation to feel like they are having their concerns about their risk taken seriously by healthcare providers.

In the present study, some of the participants identified times when their request for breast cancer screening was denied by a family physician. These events made the participants feel like their fears and/or concerns about their risk for HBC were dismissed. Even when a participant was referred for mammogram screening by a family physician, there were times when the dismissive and questioning attitudes of employees at a screening clinic made them feel as if they were *wasting peoples' time*. The frustration that some of the participants experienced led them to advocate for their breast health with other physicians. During the time of this study, all of the participants were being followed by experts at the HBOC clinic bi-annually. Although their appointments at the HBOC clinic represented points in time when they felt anxious about their risk, the clinic was also a space where they felt cared-for. It was a space where some of the participants felt like they no longer had to advocate for their right to be followed as a high risk

client. It was also a space where the close relation they had with the healthcare providers eased some of the worries they carried about their risk for HBC.

In addition to the importance of a close connection with an expert in HBC, several women expressed how the support they received from family members and friends helped them to move out of those dark spaces where they became fearful about their risk. In recognition of the importance of having family support during screening appointments, clinicians at the HBOC clinic encourage women to schedule sister/family appointments on the same day. Several participants in the present study commented on how comforting it was to go to the clinic with their relatives.

Outside of their breast cancer screening appointments, several participants expressed how helpful it was to be able to share openly with other family members and partners their anxieties and fear about their risk for HBC. Being able to share concerns about one's risk for HBC with family members and friends was identified in an earlier study as an important source of support (Appleton, et al. 2000). For example, as one woman recalled in the present study times when cancer in the family *sucked* her *into a black hole* where she worried about her risk, she found that talking about it with her husband, sister and mother helped her come out of that space.

Additionally, the way that close relatives of these women coped with a breast and/or ovarian cancer diagnosis and lived their lives as cancer survivors made for some of the women the possibility of being diagnosed with breast cancer *less scary*. Hence, certain relations between the participants and their healthcare providers and family members/friends impacted the perspectives that some of the participants had about cancer and had a grounding effect in that these relations helped the participants to balance and cope with their fears and anxieties. Outside of the preceding experiences that revealed why these participants moved into a what-if space and

what helped them to move out of these spaces, several participants talked about the positive side of living with risk for HBC and how the perceptions of others about their risk sometimes made them feel like there was something wrong with them.

The Positive Side of Living with Risk for HBC

In the present study, several participants expressed how an awareness of being at-risk for HBC prompted them to reflect deeply on what they wanted to experience in their lives and to appreciate living life in the moment. In a sense, it freed some of the participants to not stress about the *small things* as they evaluated what was important in their lives. For one of the participants, when she put aside the stress of the *what-ifs* she sometimes carried and consciously tried to live in the moment, she stated that she was *just able to be myself* and was *more thankful and able to enjoy the moment.* Focusing on living life in the present and reassessing what is important in one's life were identified by Appleton et al. (2000) as positive coping strategies that some of the unaffected women in their study used to adapt to living with an increased risk for HBOC. Given that several participants in the present study talked about how living with risk for HBC influenced the way they experienced life – i.e. taking risks and/or seizing opportunities to experience certain things in the present rather than putting it off for some day in the future – we can interpret living life in the moment as a positive aspect of living with risk.

Is There Something Wrong With Me?

Previous research on women living with a BRCA mutation found that as some of the women entered a surveillance program they started to identify themselves as either ill or a future patient (Di Pietro, et al. 2004; Underhill & Dickerson, 2011). This was not the case for the participants in the present study. Overall, the participants referred to themselves as healthy with high or a higher than average risk for developing breast cancer in their lifetime. Similarly, a

group of affected women learning of a personal uninformative negative DNA test result referred to themselves as at-risk (Maheu, 2009). However, even though the participants in the present study did not identify themselves as unhealthy, some of the participants voiced how the information they either read over the internet, perceptions of friends and relatives about their health, and/or reactions from life insurance agents to their surveillance routine implied in some way that they were either not healthy and/or could take control of their risk.

For the most part, these participants tried to maintain, for their general health, a healthy lifestyle and ignored unsubstantiated health claims over the internet or messages from friends/relatives that implied they needed to take extra care of their health to prevent cancer. One insight that arose from conversations about their health was how the perceptions of healthcare professionals often conflicted with the perceptions of non-medical people. Whereas the healthcare professionals perceived the health status of these participants as healthy with risk for HBC, there were times when comments from friends and/or relatives about what they should add or change in relation to their lifestyles as well as experiences with life insurers made them feel as if they were not healthy.

Certain societal beliefs that suggest we have control over our health and can prevent disease through our own actions, i.e. through changes in our diet, exercise regimes, and/or changes in our emotions, sends a message that as individuals it is our responsibility to take certain steps to maintain good health and prevent disease. Additionally, the definition of good health has changed as certain health disciplines and insurers integrate the absence of risk for future disease into their definition for good health (van Hoyweghen, Horstman & Schepers, 2006). The assumption that as individuals we can control our health and that being in good health means there is no known risk for future disease can be a heavy burden to carry. Although

there is no easy answer to this dilemma in an age where false or misleading health claims come and go in the media from one week to the next, future research that explores how the health of women living at-risk for HBC is perceived by the general public may point to areas where more attention to education is needed in order to change current misperceptions.

Study Limitations

In the present study, all of the unaffected women were Caucasian and were followed bi-annually by experts at an HBOC clinic. Although being Caucasian and participating in regular screening at an HBOC clinic was not a limitation, the findings cannot reveal the impact of different cultural beliefs pertaining to risk or how unaffected women who are not closely followed by experts experience living with risk for HBC. Future research in these populations can expand our understanding of how risk for HBC is experienced in the lives of unaffected women, living in BRCA negative families, who may not be followed closely in the healthcare system and may provide insights on the impact of cultural beliefs on risk management behaviour.

One limitation that merits consideration is the difficulty in quantifying risk for HBC in the study population. Although research-to-date has shown that most BRCA negative families do not have an increased risk for ovarian cancer, in this homogenous sample of unaffected women living in BRCA negative families, two sister dyads from two families in the present study had a strong enough ovarian cancer history to merit consideration for risk-reducing ovarian cancer options (Metcalfe, et al. 2009; Kauff, et al. 2005). Therefore, it could be that that there is a wide range of risk in this sample of women given that two of the families had ovarian cancer in their family pedigree. What was known was that these women were eligible to be followed at an HBOC clinic due to their projected lifetime risk for breast cancer of at least 20%. Thus, moderate

or high risk labels were not used in this study, Instead, the women in the present study were referred to as being at-risk for hereditary breast cancer.

CHAPTER 6: CONCLUSION

The focus of the present study was to understand how risk for HBC impacted the day-to-day lives of unaffected women who live in BRCA1/2 negative families. A hermeneutic phenomenological approach was used to uncover meanings within the experiential descriptions the nine participants provided and to gain an understanding of how these experiences affected the way they experienced lived space, time, body, and relations.

Key Findings

Moving In and Out of the What-ifs. Although all of the participants voiced that they spent most of their time in a normal life space where they got on with and enjoyed their lives with an awareness of their risk for HBC in the background, this research afforded a glimpse into the ways in which these participants shift in and out of the what-if spaces. What-if spaces were referred to by the participants as dark spaces where they contemplated and stressed over what could happen. Certain events or markings in time shifted the participants into the what-if spaces where they confronted their mortality and experienced anxiety and/or fear over their risk for developing or being diagnosed with HBC. For many participants it was the close and supportive relationships they had with their healthcare providers, family members, and friends that pulled them out of that dark space where they temporarily felt anxious and/or fearful about their risk. Additionally, experiencing positive attitudes among family members diagnosed with cancer, seeing how their affected relatives continued to enjoy their lives as survivors, and being followed closely at an HBOC clinic imbued hope and made the prospect of having cancer a little less scary for many participants. Another interesting insight that emerged from their conversations about living with risk for HBC was how the awareness of their risk led many participants to focus on living and enjoying life in the present. This is a positive side of living with risk that has been

documented in other studies that focused on the experiences of women living with a known BRCA mutation.

It is also important to consider that although all of the participants in the present study commented on the reassurance, relief, and close connection they felt in being followed by experts at an HBOC clinic, several participants identified times prior to their attendance at the clinic when they felt like their fears and concerns about their risk were dismissed and/or questioned by physicians and allied healthcare professionals. It was as if they were outsiders looking in on a world where those who were either identified as BRCA mutation carriers or were cancer survivors were the only ones taken seriously. This finding should make us wonder and investigate in future research whether these experiences are anomalies or more widespread than we think.

Indecision Surrounding Risk-Reducing Options. Another important finding related to the indecision that many participants experienced as they contemplated whether they would undergo and the timing of a risk-reducing surgery. Although the participants who were considering a prophylactic surgery spoke of different parts of their lives that would be affected – i.e. relations with spouses and/or the physical and emotional effects of instant menopause – not knowing what it was genetically that might explain the number of cancers in their family and not knowing if they could be carrying this undiscovered mutation made, for some of the participants, the decision to undergo a prophylactic surgery that much harder.

What is Good Health? Lastly, an important insight that emerged from the conversations in this research was the conflicting perceptions related to how good health is defined between medical and non-medical people. Whereas the participants themselves did not feel that being at-risk for HBC meant that they were unhealthy, they identified instances where comments from friends,

relatives, and/or insurance agents about their health and how they should take special care of themselves to prevent cancer from happening made them feel as if they were not healthy. These experiences speak to how technology (consisting of a body of knowledge and way of re-organizing our way of being-in-the-world) in predictive medicine may have changed our collective definition of good health.

Implications

Practice and Future Research. The experiences that the participants told in relation to living with risk for HBC provided many insights that give healthcare professionals an understanding of the different ways in which risk may temporarily impact the lives of their patients. Learning through the stories of these participants provides healthcare professionals with several possible ways of experiencing living with risk to bear in mind as they delve into the life stories of other patients who are living with risk for HBC. For example, living with risk may impact the way a woman experiences time. Some women may direct their energies to what they can experience and enjoy in the present rather than putting things off into the distant future. This lens can be positive as long as a woman does not internalize her risk as limiting to the point where there is too much pressure to experience certain events in the present. Additionally, the insights gleaned from this study illuminates how powerful human relationships are in helping these women to stay grounded rather than feeling overwhelmed by their risk. For example, many of the participants expressed how the support they received from close family members and friends helped them to put their risk into perspective during emotional times when a relative was diagnosed with or living with a terminal cancer diagnosis. Some of the participants also expressed how the positive outlooks they experienced among family members, even among those who were dying, helped them to move through their personal fears. Thus, within the

relational space between healthcare professionals and unaffected women at-risk for HBC, it can be beneficial to a woman's well-being to allocate time to discuss how the familial context and the support they receive from others impacts the way they live with risk.

Although the present study is but one exploration into the lives of a small number of unaffected Caucasian women living with risk in the absence of a known BRCA mutation, the findings provide a foundation for the following future lines of inquiry:

1) How does knowledge in predictive medicine alter our definition of good health in the public sphere?
2) How do unaffected women in other cultures experience living with risk for HBC?
3) How do unaffected women, who are living with risk for HBC and are not being followed by experts in a HBOC clinic, perceive the care they receive from their general healthcare practitioners in relation to their risk?
4) What does the term "good health" mean to unaffected women living with risk for hereditary breast cancer?

The lines of inquiry suggested above may further inform the practices of healthcare professionals providing care for these women and provide evidence based support for changes in current healthcare policies.

Policy and Education. Current public health policies and education is another area that may benefit from the insights gleaned from the present study. Given that there is no evidence to support the belief that eating a healthy diet will prevent a woman from developing breast cancer, it could be beneficial for policy makers to evaluate how public health messages about risk reduction behaviours for cancer are being interpreted by the general public. Also, the findings from this small group of participants point to a need for educators/researchers to examine

knowledge levels and attitudes about screening programs among healthcare professionals. Lastly, not all HBOC clinics follow high risk unaffected women who are not eligible for BRCA genetic testing. Being followed by experts at an HBOC clinic was expressed by the participants in this study as a positive experience that helped to ease their anxieties and/or fears. Future research should examine the psychological and economic benefits of including this population of women in all HBOC clinics.

A Personal Narrative

As I began my personal journey with breast cancer, I found myself delving into books on the history of breast cancer and searching for articles to understand how other women experienced this disease. My increasing curiosity about how other women experience living with breast cancer and a review of the literature led me to wonder how unaffected women (with no personal history of breast and/or ovarian cancer) experienced living within families where there was a strong family history of breast cancer. My decision to study the experiences of these women for my dissertation prompted me to question my position as the patient moving over to the role of the researcher. This shift made me wonder how the context of my experience could bias my interpretation of the stories presented by these women.

The term "bias" implies that one has a preconceived notion of the subject matter that may colour and/or guide the research question as well as the interpretation of data. Since removing researcher bias completely from the study design, implementation, and analysis in qualitative research is viewed as both impossible and undesirable (Lincoln & Guba, 1985), it is imperative to critically assess how the influence of researcher bias may be understood and reduced throughout the study. As the researcher, I constituted the meaning of the phenomena that was presented through the lens of my prior experiences. Therefore, it behooved me to examine my

preunderstandings and assumptions of the phenomena before and as the phenomena was presented to consciousness. It is through this work, often referred to as reflexivity, that I became more aware of myself in order to remain open to the other's phenomenological point of view (Munhall, 1994). Thus, the narrative below provides a personal description of my experience as I learned of my cancer diagnosis and some insights that I learned about myself through my reflective writings during the present study.

During the second semester of my doctoral studies I felt a small lump in my left breast. I woke up three mornings in a row with an itch along the outside of my left breast. The first two days, I scratched lightly along the skin of my breast for relief – but on day three I dug deep into the tissue and found a hard substance the size of perhaps a pea. It still amazes me that after I found the lump the itchy sensation I felt for three days disappeared. At first, my mind went to a cyst as the cause since a Radiologist found one in the same spot a couple of years prior to that day. To be sure, I went to the medical clinic at the university to have a doctor take a look. He also thought it was a cyst but wanted me to go for a mammogram and ultra-sound to be on the safe side. I booked my appointment for the following week and didn't think much about the possibility of it being malignant – in fact I do not recall feeling any anxiety leading up to that appointment. How could I have cancer when the screening mammogram I had seven months prior to this discovery had been clear and there was no history of breast cancer in my family? How wrong I was... Although the mammogram I had the following week was still clear, the Radiologist examined the growth on the ultrasound and stated "it has all the characteristics of being cancer". Instantly, the darkness of the room closed in… I found myself squeezing my nose with my right hand in an attempt to somehow stop me from feeling anything other than the pain I was causing myself. The words "characteristics of being cancer" from the Radiologist's lips left

me speechless - as I struggled to take a breath all I could do was fixate on a little black spot on the screen. This questionable spot had the power to forever change the way I viewed my place in the world and marked the beginning of a journey that somehow disengaged who "I" was, with a growth that would become a separate object to annihilate and ruminate over the chances of its reappearance.

Two weeks later, I found out that the growth was indeed malignant. My personal diagnosis of breast cancer led me down a path of angst and uncertainty as I moved from the diagnosis to surgery and then onto radiation and pharmaceuticals to decrease the risk of my body repeating the proliferation of these rogue-like cells. Along the way, I was met with a barrage of statistical models – models that were supposed to circumvent my worst fear of prematurely leaving behind an eight year old daughter. The quest to explain and predict took over my world as I spent many nights in front of the computer – mesmerized by breast cancer survival rates and possible causes. Even the language I used to explain my diagnosis and prognosis was scientific and void of emotion or personal meaning. I now identified myself as one with stage I invasive breast carcinoma with a histological grade of I and a 10 year survival rate of "xyz"…

After hearing medical specialists go through a list of probabilities such as the 5 and 10 year survival rates, recurrence rates when undergoing a mastectomy versus a lumpectomy with radiation, and other risks associated with chemoprevention drugs, I craved a safe space to move away from the onslaught of predictions and unload my deepest fears with others who were experiencing something similar to what I was going through. However, the support group that I attended seemed to be replaying all of the statistics and scientific labeling that I had already heard. As we went around the room one by one to hear each other's story, I heard these women talk about their experience primarily in terms of the stage and histology of the disease and the

probabilities of "conquering" cancer with certain treatments. I began to wonder if it was easier to somehow distance ourselves from the heaviness of cancer by re-presenting this disruption in our lives as one that was defined and managed through a medical narrative that focused on treatments and statistical probabilities.

Although I am deeply grateful for the scientific knowledge, technology, and the expertise of oncology clinicians, I noticed that the positive statistics I heard in relation to my probabilities for survival did not take away the dreadful feeling of uncertainty I felt when I looked into the eyes of my daughter. Thus, it was this revelation that turned my attention to the subjective experiences of women touched by breast cancer in the qualitative research literature. My decision to explore the lived experiences of unaffected women living in families where a known BRCA gene mutation could not be identified in an affected family member came about through a broad search to understand what was known about the experiences of affected and unaffected women living with hereditary risk for breast cancer.

Through this search, I found that little was known about the experiences of unaffected women. Once I started the recruitment phase of this research, I was struck by the eagerness of several women to tell me their story. During our first conversational interviews, several women naturally started their story from the time they became aware of there being hereditary risk for breast cancer in the family. As I delved into their past experiences by way of our conversations and the text, I found myself feeling the joys, fears, and grief of these women. As I tried to imagine being in their shoes, I realized how stark a contrast there was between my upbringing, where cancer usually did not present itself in family members until very late in life, to their experiences where breast and/or ovarian cancer was experienced through close family members diagnosed with the disease when the women in this study were children or young adults. As I

went through most of my life not giving much thought to breast cancer, these women lived with the threat that they could be next from a very young age.

When I started the study, I was not sure how I would react to their stories. Their stories touched me in a way that I never imagined. For example, when Adele became emotional as she recalled a time when one of her grade two students experienced the death of her mother due to breast cancer and she found herself imagining that the girl's mother could be her one day, I found myself tightening my whole body in order to hold back my tears. Although I was successful in holding back my emotions during that conversation, listening to the tape a few days later resulted in an emotional release.

Being immersed in the stories these women shared also made me feel more anxious than usual about a pending mammogram screening appointment. At that moment, I started to feel like I was in an easier or should I say lighter space than these women for I do not have a family history of breast cancer to remind me of a hereditary threat. I feel as though I am in this space because I found out I had cancer after my daughter was born and never had to consider a risk-reducing surgery. Although I now know that my daughter will likely be monitored earlier in life for breast cancer, I never went through any angst about the possibility of passing an undiscovered hereditary gene mutation to her, nor did I need to undergo intensive surveillance tests early in life. I can only imagine through these women's stories how hard it must sometimes be to watch close family members live with or die from a hereditary cancer, to be reminded through their family history that they could be next, and to make decisions about certain risk-reducing options at a time in their lives when many of us are not thinking about our mortality. Thus, the thoughtful attentiveness I paid to the experiences these women told and reflections on my own lived experiences as well as the ways in which their stories touched me, helped me to

craft a text that brought “into visibility or nearness”… “the hidden, invisible, originary aspects of meaning that belong to the prereflective” lifeworlds (van Manen, 2014, p. 221) of these women in relation to living with risk for hereditary breast cancer.

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APPENDIX A: REFERRAL CRITERIA FOR HEREDITARY CANCER SYNDROMES:

Specific Criteria for HBOC Syndrome

1. Relatives of an individual with a confirmed pathogenic BRCA1 or BRCA2 mutation.

Breast Cancer

1. Personal history of breast cancer diagnosed before age 40.
2. Personal history of breast cancer diagnosed before age 50, AND a first or second degree relative with breast cancer diagnosed before age 50.
3. Personal history of breast cancer, AND two related family members with breast cancer diagnosed at any age, spanning two generations.
4. Personal history of more than one primary breast cancer, one diagnosed before age 50.
5. Personal history of "triple negative" tumour (ER-ve, PR-ve, Her2-ve).

Ovarian Cancer

1. Personal history of invasive serous ovarian cancer diagnosed at any age.
2. Personal history of ovarian cancer diagnosed before age 50.
3. Personal history of ovarian cancer diagnosed at any age, AND a first or second degree relative diagnosed with ovarian cancer at any age.

Breast and Ovarian Cancer

1. Personal history of both breast and ovarian cancer diagnosed at any age.
2. Personal history of breast cancer diagnosed before age 50 AND a first or second degree relative with ovarian cancer at any age.
3. Personal history of male breast cancer diagnosed before age 65 AND a first or second degree relative with breast or ovarian cancer diagnosed at any age.

Ashkenazi Jewish Ancestry

1. Personal history of breast or ovarian cancer diagnosed at any age (genetic testing is limited to the Ashkenazi mutation panel followed by a full screen ONLY for individuals who meet other criteria).
2. Unaffected individuals with a first degree relative with breast cancer diagnosed before age 50, ovarian cancer diagnosed at any age, male breast cancer diagnosed at any age, or multiple related relatives with breast and/or ovarian cancer diagnosed at any age (genetic testing is limited to the Ashkenazi mutation panel ONLY).

Other

1. Families who have a significant clustering (above general population prevalence) of breast and/or ovarian cancer, but who do NOT meet above criteria (for assessment only).

(adapted from Alberta Health Services, 2012)

APPENDIX B: INCLUSION CRITERIA

Introduction Letters about the study were handed out by a Licensed Practical Nurse on an HBOC Clinic day to women who met the following inclusion criteria:

- female, between 18 and 70 years of age
- has no previous personal history of cancer and has not undergone BRCA genetic testing
- is identified as having at least a 20% lifetime risk for breast cancer
- has at least one 1st or 2nd degree affected relative who has undergone BRCA genetic testing and has received an uninformative negative result
- a known or unclassified BRCA mutation has not been identified in the family
- speaks English
- resides within 3 hours driving distance from Edmonton

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APPENDIX C: INVITATION/LETTER OF INTRODUCTION TO THE STUDY FOR POTENTIAL PARTICIPANTS

INVITATION

Study Title: Living at-Risk for Hereditary Breast Cancer: The Experiences of Unaffected Women Who Live in Families Where a BRCA Gene Mutation Could Not be Found

Doctoral Student: Dawn Schroeder, RN, MPH, PhD Candidate

Study Supervisor: Dr. Wendy Duggleby, Professor, Faculty of Nursing, University of Alberta, Edmonton, Alberta

You are invited to take part in a study to talk about what it is like for you to live in a family with hereditary risk for breast cancer. My name is Dawn Schroeder and I am a nurse and doctoral student at the University of Alberta. I would like to talk to women who do not have a personal history of cancer and live in a family where a BRCA genetic mutation has not been found. The results of this study may help doctors and nurses understand how women experience living with hereditary breast cancer risk and what this risk means to them. If this study interests you, you will be asked to meet with me at least once or more if you would like to talk about your experience. Each conversation with you will be tape recorded. Child care, transportation, and parking costs will be provided. You may stop the conversations at any time with no penalty.

For this study, Dr. Wendy Duggleby is my supervisor and can be contacted at: (780) 492-8660 or by email at: wendy.duggleby@ualberta.ca. **If you would like to learn more about this study, please contact Dawn Schroeder either by telephone: (780) 668-8856 or email:** adschroe@ualberta.ca.

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APPENDIX D: INFORMATION LETTER FOR PARTICIPANTS

Study Title: Living at-Risk for Hereditary Breast Cancer: The Experiences of Unaffected Women Who Live in Families Where a BRCA Gene Mutation Could Not be Found

Investigator: Dawn Schroeder, RN, MPH
Affiliation: PhD Candidate, Faculty of Nursing, University of Alberta
Email: adschroe@ualberta.ca
Phone: (780) 668-8856

Supervisor: Dr. Wendy Duggleby
Affiliation: Faculty of Nursing, University of Alberta
Email: wendy.duggleby@ualberta.ca
Phone: (780) 492-8660

Purpose of the Study

You have been invited to take part in this study because you live in a family where there is a hereditary risk for breast cancer and a BRCA gene mutation has not been found. Dawn Schroeder is conducting this study for her PhD in Nursing and is the main researcher. The purpose of this study is to explore through one-on-one conversations what it is like for you to live with risk for hereditary breast cancer. The results of this study may help doctors and nurses understand how women experience living with hereditary breast cancer risk and what this risk means to them.

What the Study Involves

This study involves 2 or 3 audiotaped conversations that will take approximately 30 to 60 minutes at a place and time that is convenient for you. In the first conversation, you will be asked to talk about living in a family at-risk for hereditary breast cancer and what the presence of a hereditary risk for breast cancer means to you. The second and third conversations will take place within two months of the first conversation to confirm what the experience of living in a family at-risk for hereditary breast cancer is like for you. You may be asked to clarify and/or comment on some of the things you talked about in a prior conversation. In recognition of your time for this study, you will receive a $25.00 gift certificate at the end of the first conversation. This gift certificate will be offered even if a second or third conversation does not take place.

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Risks and Benefits

Talking about hereditary risk for breast cancer may be upsetting. If you start to feel upset as you talk about your experiences, I will ask you if you would like to talk about something else or stop the conversation. If you feel upset during one of the conversations, I will advise you to call Kyla Sorel, the Allard Hereditary Breast Ovarian Cancer team psychologist, at (780) 297-7578 and/or contact your family doctor.

One of the benefits to you for taking part in this study may be the opportunity to talk about what it is like for you to live within a family at-risk for hereditary breast cancer. The findings from this study may help doctors and nurses become aware of what it means for some women to live in a family where there is a risk for developing hereditary breast cancer. A copy of the study results will be given to you upon your request from Dawn Schroeder.

Refund for Expenses

Expenses will be refunded to you for your participation in each conversation as follows:

Childcare @ $8.00 per hour
Bus Fare
Mileage @ 0.48 per kilometer
Parking Fees

Voluntary Participation

Your participation in this study is completely voluntary. You can refuse to participate and/or leave the study at any time without giving a reason for your withdrawal. If you withdraw from the study, the written data from your stories will be combined with the stories of other participants. Leaving the study will not affect in any way the healthcare you receive in the province of Alberta. You can also refuse to answer any questions asked throughout the study.

Privacy and Confidentiality

All data from this study will be kept confidential and locked in a cabinet for 5 years before being destroyed. Voice recordings will be encrypted then erased after 5 years once the study is complete. The results of this study will be included in a dissertation thesis, a manuscript for a journal article, a poster presentation for a conference, and an executive summary. Your name will not appear in any reports of the study results or talks about the study. The results of this study may also be used in the future to answer other research questions. Future use of the results from this study in future studies will be subject to a review by an ethics review board.

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Contact Information

If you have any questions about this study, please contact Dawn Schroeder at (780) 668-8856, or adschroe@ualberta.ca. Dawn Schroeder will be available for the duration of the study to answer your questions about the study. If you have any problems with the study, you can contact Dr. Alexander Clark, Associate Dean of Research, at the University of Alberta, Faculty of Nursing, at (780) 492-8347 or alex.clark@ualberta.ca. Dr. Alexander Clark is not involved with this study.

The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

Yours truly,

Dawn Schroeder, RN., MPH, PhD Candidate
University of Alberta

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APPENDIX E: CONSENT FORM FOR PARTICIPANTS

Study Title: Living at-Risk for Hereditary Breast Cancer: The Experiences of Unaffected Women Who Live in Families Where a BRCA Gene Mutation Could Not be Found

Study Supervisor:
Dr. Wendy Duggleby
Faculty of Nursing
University of Alberta
wendy.duggleby@ualberta.ca
780-492-8660

Study Investigator:
Dawn Schroeder, RN, MPH
PhD Candidate
Faculty of Nursing
adschroe@ualberta.ca
780-668-8856

Consent of Participant	**Yes**	**No**
Do you understand that you have been asked to be in a research study?		
Have you read and received a copy of the attached Information Letter?		
Do you understand the benefits and risks involved in taking part in this research study?		
Have you had an opportunity to ask questions and discuss this study?		
Do you understand that you are free to leave the study at any time, without having to give a reason and without affecting your future medical care?		
Has the issue of confidentiality been explained to you?		
Do you understand that your conversations with Dawn Schroeder will be audiotaped?		

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Consent Form Signature Page

This study was explained to me by:_____

Date:_____

I agree to take part in this study.

Signature of Research Participant:_____

Printed Name:_____

Date:_____

Signature of Witness (if available):_____

Printed Name of Witness:_____

I have explained this study to the best of my ability. I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

*Signature of Researcher:*_____

Printed Name of Researcher: _____

*Date:*_____

*A copy of this consent form must be given to the participant.

APPENDIX F: CONVERSATION/INTERVIEW GUIDE

Opening Statement

I am interested in learning about what it is like for you to live with risk for hereditary breast cancer. Please feel free to share any thoughts or feelings that you have about your experience. Could you please tell me your story about what it is like for you to live with a hereditary risk for breast cancer?

Prompting Questions

The following questions are examples of the type of questions I may ask during the conversations if the women do not answer these questions during our conversations:

1. What was it like for you to learn that there is a hereditary risk for breast cancer in your family?
2. What does hereditary risk for breast cancer mean to you?
3. What was it like for you to learn that a BRCA1/2 gene mutation was not found when a relative underwent genetic testing?

Prompts to elaborate on an aspect of the conversation:

1. Can you give me an example of that?
2. Can you tell me more about that?
3. How did you feel about that?