# "You're Armed, I Think You're Better Armed": Women's Opinions of Genetic Counselling and Testing for Hereditary Breast and Ovarian Cancer Susceptibility (BRCA1)

by

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## Abstract

Opinions of those who went through genetic counselling for hereditary breast and ovarian cancer risk were sought on genetic counselling and genetic testing for BRCA1. The majority of those interviewed were happy with the genetic counselling received and had generally positive attitudes towards genetic testing for BRCA1. Information gained was considered important and provided a sense of control and avenues for further action. Family experience with cancer also appeared important in how individual women perceived their risk. Correspondingly, biomedical knowledge provided by genetic counselling and testing was mediated by and combined with personal experiences to create an embodied knowledge of risk.

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# Contents

Abstract ii
Contents iii
List of Tables and Figures v
Acknowledgements vi
Chapter 1: Introduction 1
Chapter 2: Literature Review 4
  Hereditary Breast and Ovarian Cancer 4
  Breast Cancer Gene Testing in British Columbia 7
  Cancer, Genetic Testing & Society: The Wider Context 9
    Cross Cultural Oncology: How is Cancer Shaped Culturally? 9
    Cancer Causes and Prevention 13
    Genetic Testing and Society 17
    Genetic Testing and the Individual 21
      Psychological Effects 21
      Men and the Psychological Effects of Testing 22
  Risk Perception and Embodied Knowledge 23
Chapter 3: Research Methods 29
  Interviewees 33
Chapter 4: Findings 35
  Genetic Counselling 37
    Information Provided by Genetic Counselling 38
    Gateway Access to Medical Services 41
    Emotional and Social Benefits of Counselling 41
    Reservations about Counselling 44
    Genetic Counselling: A Summation 47
  Genetic Testing 49
    Benefits 49
      Control over Health 49
      Access to Medical Support 51
      Closure of Worries 52
      Societal Benefits 53
    Disadvantages 54
      Emotional Distress if Positive 54
      Discrimination: Life insurance, employment, and social interaction 55
      Reproductive choices 57
    Views of Those Ineligible for Testing 60
    Dissenting Voices 63
    Advice 63
  Risk Perception and Action 67
    Negative Test Results 67
    Positive Test Results 70
    Ineligible for Testing 76
    Cancer Prevention 80
    Cancer Hopes 83

Chapter 5: Discussion ........ 85
  Cultural Trends & Social Factors ........ 85
    Information, Culture, & Identity ........ 85
    Perceived Cancer Causes ........ 88
    Genetic Testing and Life Decisions ........ 89
  The Individual: Embodiment of Knowledge: Risk Negotiation & Action ........ 91
    Negotiation of Biomedical Knowledge ........ 91
      Ambiguity ........ 91
      Personalizing Statistical Risk ........ 92
      Counselling as Reinforcement ........ 94
      Modification of risk by Personal Characteristics ........ 95
    Embodied Knowledge ........ 95
  Societal Trends and Individual Endeavors ........ 98
Chapter 6: Conclusion ........ 100
References Cited ........ 103
VITA ........ 118

# List of Tables and Figures

List of Tables:

Table 1. Lifetime risks of breast and ovarian cancer for Canadian women with and without a cancer susceptibility mutation. 6
Table 2: Location, Test Status and Gender of those interviewed. 31

List of Figures:

Figure 1. Incidence of sporadic versus hereditary breast and ovarian cancer (Cannon-Albright and Skonick 1996). 5
Figure 2. Flow diagram for the genetic testing process in British Columbia. 8

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*For one in nine Canadian women*

# Chapter 1: Introduction

Breast cancer, with an incidence of 1 in 9 (National Cancer Institute of Canada 2000b), represents a serious threat of morbidity and mortality to Canadian women. One of the ways in which breast cancer research has progressed is by focussing on those families where the number of cases of breast cancer is high. In 1994, mutations in a particular gene, BRCA1, were linked to an increased susceptibility to both breast and ovarian cancer (Miki et al. 1994). This was followed by the discovery of BRCA2, a similar gene (Wooster et al. 1995). As a result of these discoveries, it is now possible to offer genetic testing to individuals who have a strong family history of breast and or ovarian cancer to determine if they have an increased risk of breast and ovarian cancer. In BC at the time of this study, this testing is started as part of an ongoing research protocol, however as of 2000, it is now provided on a service basis.

As is the case for any emerging medical technology, it is important to understand how the test affects the individuals who use it. A qualitative exploration is useful in determining broader implications and ramifications to those who are offered testing: how those tested evaluate the genetic counselling that accompanies genetic testing, how they perceive their risk and what actions they pursue as a result of that risk perception, and also the opinions of those ineligible to be tested under the criteria for testing. My original goals for this study, therefore, were to seek the opinions of those who have testing about genetic testing, to look for areas of miscommunication or areas that required improvement in the genetic counselling (thus providing the most applied potential of the research). Also, to examine how women viewed their risk and what actions they thought were appropriate to combat contracting cancer. For the latter issue, I was specifically interested in examining people's opinions about whether cancer could be prevented, through lifestyle, diet, vitamins, and exercise, as well as early detection measures, such as breast self exam, mammography, and exam by a physician.

When I began interviewing, I discovered that the majority of individuals that I spoke to were positive about genetic counselling and testing. They placed a great value on the information they received through testing, and seemed pleased with counselling. Issues of contention with counselling concerned who was eligible and delays, rather than with the communication itself. Another feature common to the interviews was that conceptions of risk were heavily tied to family experience with cancer, but for prevention and screening, most women's opinions paralleled recommendations of the medical establishment.

There is a divergence, then, between the opinions of those interviewed and the social science literature, which mostly questions the use of genetic testing as a technology (for genetic testing in the context of amniocentesis and cancer susceptibility). Workers in this field raise concerns about the possibilities for genetic discrimination, in both the life insurance industry and by employers. Some suggest it could change the reproductive options open to those labeled as 'genetically abnormal', or generally turn genetic testing into a process where people are identified as having personal flaws. Disease would therefore be not a larger social problem, but rather the responsibility of individuals with 'bad genes'. Furthermore, other authors question the direction of cancer research. Some examine cancer research and fundraising as a dialogue playing on the concept of hope, while others question the focus on genetics taken by cancer research, pointing to larger environmental concerns which are seen as less valued.

One of the ways to reconcile such a divergence is to examine the role of genetic testing for breast and ovarian cancer susceptibility as it operates at two levels: the societal or cultural level and the individual level. Both are equally valid and important, however the benefits and disadvantages to genetic testing can differ depending on which level one is examining. What may have been beneficial to the women interviewed here may not be so positive when viewed from the cultural level.

# Chapter 2: Literature Review

## Hereditary Breast and Ovarian Cancer

A hereditary predisposition accounts for approximately 5-10% of all cases of breast and ovarian cancer (Cannon-Albright and Skonick 1996;Welcsh et al. 1998). The other 90-95% of cases occur sporadically, with no apparent heritable component.

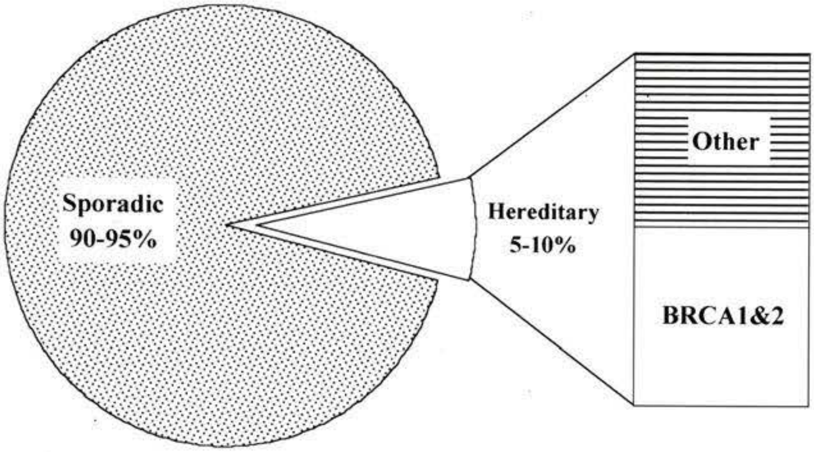

Figure 1. Incidence of sporadic versus hereditary breast and ovarian cancer (Cannon-Albright and Skonick 1996).

Mutations in two genes, BRCA1 and BRCA2 (for breast cancer 1 and 2) are associated with a susceptibility for breast and ovarian cancer and are thought to be responsible for less than 80% of the hereditary cases (Couch et al. 1997;Ford et al. 1998), possibly around 50%. Genetic susceptibility for cancer means that an individual will have an increased risk of developing cancer. BRCA1 was discovered in 1994 (Miki et al. 1994) followed shortly after by the discovery of its counterpart, BRCA2 (Wooster et al.

1995). A woman with a BRCA1 gene mutation has been suggested to have a 50-85% lifetime risk of developing breast cancer and a 16-60% risk of developing ovarian cancer (Easton 1997;Struewing et al. 1997). Risks for BRCA2 mutations are similar for women, but carry a higher risk of breast cancer for men (Easton 1997). Early estimates for these genetic mutations, based on cancer incidence in families with many cases of cancer were at the higher end of this scale (85% and 60% respectively), but subsequent population studies have questioned this estimate and provided lower estimates, widening the range (Struewing et al. 1997). It is unclear why this difference exists. It is possible that specific mutations within BRCA1 & 2 could provide different risks, not only of cancer incidence, but also of cancer type (ovarian or breast) (Struewing et al. 1997). Particularly since over a hundred mutations of various types have been identified in the BRCA1 gene, these could have separate effects (van Golen et al. 1999). Alternately, differences in risk between population based studies and family studies could be explained by other factors, either genetic or acquired that run in families and modify the effects of the genetic mutation (van Golen et al. 1999). Regardless of the specific risk figure, these risks are much higher than that of the lifetime risks of a Canadian woman without a genetic mutation: a 10.6% chance of developing breast cancer and a 1.5% chance of ovarian cancer (National Cancer Institute of Canada 2000b).

Table 1. Lifetime risks of breast and ovarian cancer for Canadian women with and without a BRCA1 cancer susceptibility mutation.

| | | |
|---|---|---|
| Breast cancer | | |
| Average Canadian woman | 11% | N.C.I.C., 2000 |
| BRCA1 mutation | 56%-85% | Easton, et al, 1995; Struewing et al, 1997 |
| Ovarian cancer | | |
| Average Canadian woman | 1.5% | N.C.I.C., 2000 |
| BRCA1 mutation | 16-60% | Easton, et al., 1995; Struewing, et al., 1997 |

BRCA1 & 2 are primarily examined in relationship to their effect on women, since men appear to be less severely affected by the genetic mutation than women are (with the exception of a BRCA2 mutation and a higher risk of breast cancer for men). However, men can pass a mutation on to their children and are also at an increased risk of prostate and gastrointestinal cancers (van Golen et al. 1999). For instance, carriers of a BRCA1 or BRCA2 mutation have an estimated risk of prostate cancer of 16% by age 70, (Struewing et al. 1997), as opposed to a lifetime risk of 11.3% for the average Canadian male (National Cancer Institute of Canada 2000b).

Increased risk is thought to occur with genetic mutations in BRCA1 & 2 by causing disruptions in the genes' function as tumour suppressor genes. When BRCA1 mutates, or is damaged, it does not function, and tumours that normally do not develop are able to grow. Experiments with mice have shown that it probably has a necessary role in embryonic development as well as in suppressing tumours (van Golen et al. 1999). Knudson's classic "two-hit" model (Knudson 1997) suggests that, generally, most people have two working copies (alleles) of a tumour suppressor gene. Both copies must mutate before the individual can develop cancer. It can take many years for these mutations to occur. This, then, explains why breast and ovarian cancers (and cancer in general) are found primarily in older individuals, as they have more time in which to accumulate mutations. In the case of hereditary cancer, however, someone is born with one copy of this gene already mutated, that is, they are born with the first "hit". The probability of developing cancer is now dependent on mutations occurring in the single remaining working copy. Hence, individuals are at greater risk of developing cancer and have a greater chance of doing so at a younger age. However, the precise mechanism by which these hits occur and cause cancer to develop through interaction with the BRCA1 and 2 genes has not yet been fully unraveled (van Golen et al. 1999). What is clear is that any genetic testing for mutations in BRCA1 and BRCA2 will only provide susceptibility information rather than predictive information. The results can only indicate whether one is more or less likely to develop cancer.

## **Breast Cancer Gene Testing in British Columbia**

In British Columbia at the time of my study, genetic susceptibility testing was offered as part of a clinical research program, however as of 2000 it is now offered on a service basis. In British Columbia at the time of my study testing was only available for mutations in the BRCA1 gene, although now BRCA2 gene testing is offered as well. However, so I will focus on BRCA1 gene mutations and testing here. There is some variation to the process of testing, but usually, a physician refers a woman to a genetic counsellor if the physician feels that her family history of breast and ovarian cancer warrants it. She meets with a genetic counsellor who reviews her family history, provides information about what her history suggests about her risks of breast and ovarian cancers, and the liklelihood of having a BRCA1/2 mutation, and informs her if she is a candidate for genetic testing under the present criteria. Currently, a woman has to have several cases of breast or ovarian cancer in her close family to be tested including at least one case of premenopausal onset of cancer (there are some exceptions). Testing must also begin with a person in the family who has previously developed breast or ovarian cancer. The genetic counsellor also explains what will actually be tested and what the results of the test might mean to the woman. Such factors as health risks, emotional distress, and other issues are discussed so that the woman can make an informed decision about whether or not to have the test, if she is eligible.

If the individual decides to be tested, the genetic counsellor and/or a clinical geneticist or oncologist will also communicate the results of the test, normally in person. They will then discuss what the results mean and what that person's best medical strategy is, given her level of risk. Women (from Vancouver Island and the Lower Mainland) are often referred to the high risk surveillance clinic at the BC Cancer Agency in Vancouver, where they can see an oncologist regularly and undergo various screening measures designed to detect breast and ovarian cancer.

**Testing Steps**

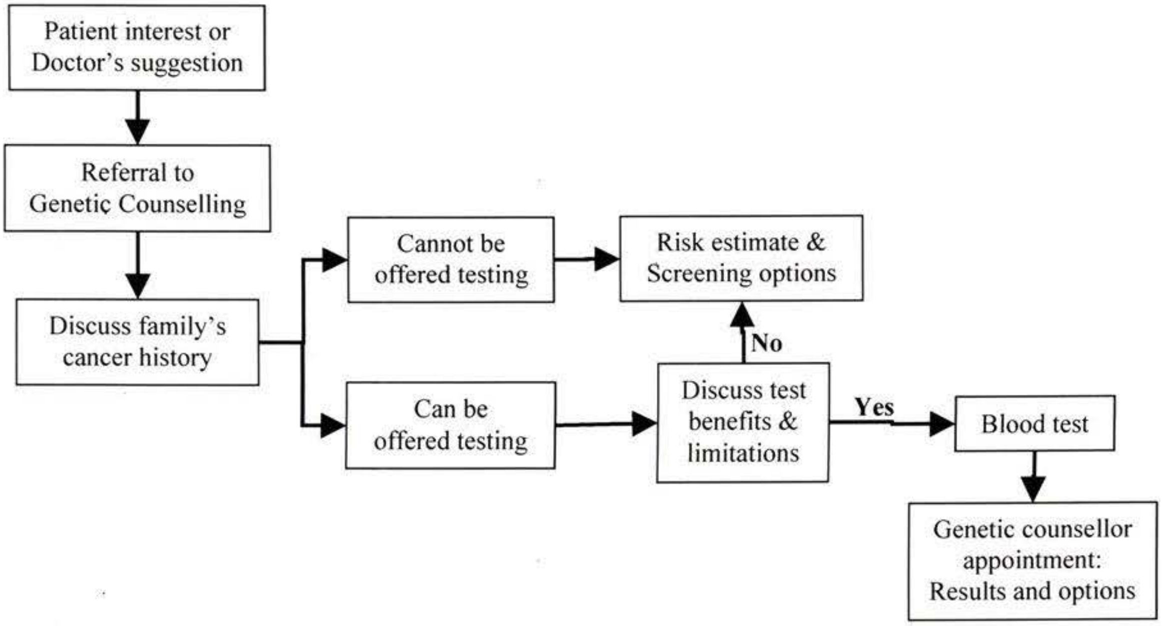

Figure 2. Flow diagram for the genetic testing process in British Columbia.

If a mutation is found in the BRCA1/2 gene of the family member who has already developed cancer, then other family members are offered the opportunity to participate in testing. This is the point at which men in affected families sometimes choose to have testing, as well as women, although fewer men than women choose testing. It is estimated that men currently make up only about 1-2% of those choosing testing for the BRCA1 & 2 genes (Myra Micek, pers. com.)

## **Cancer, Genetic Testing & Society: The Wider Context**

There are many different factors that influence the meaning surrounding a medical/technological practice such as genetic testing for cancer susceptibility. How the culture in question views the disease and its causes is important, as are societal views about genetic testing in general. All of these influence how an individual later makes decisions about whether to have testing, what it means, and what changes it brings for them.

### ***Cross Cultural Oncology: How is Cancer Shaped Culturally?***

Cancer is viewed differently by different societies, especially in terms of its potential to be cured and the best way to go about affecting a cure. Biomedicine develops local variants in different societies, which are powerfully influenced by societal and institutional contexts. These are often most apparent when looking at the more social aspects of medicine, such as the relationship between patients, their families, and their health practitioner (Del Vecchio Good et al. 1990). For example, disclosure of a cancer diagnosis is more common in some cultures than others. While disclosure of a diagnosis is considered essential ethical practice in America, it is less favorably viewed and occurs less often in Italy and Japan (Gordon and Paci 1997;Gordon 1990;Del Vecchio Good et al. 1990;Long and Long 1982;Interdisciplinary Group for Cancer Care Evaluation 1986;Swinbanks 1989).

A possible explanation for this is that different "cultural narratives", which influence and encourage different types of behaviour are at play in these countries. Gordon & Paci (Gordon and Paci 1997) suggest that medical practices such as communication of a diagnosis need to be examined within the wider context of social practice. Social practice will direct what kind of communication is appropriate, and the ideology and intent behind a particular form of communication. Thus, the meaning of the disclosure of a cancer diagnosis can be very different within one cultural narrative than it is within another. In addition, Gordon and Paci's concept of cultural narrative is useful, since several cultural narratives can be present within the same individual or country at the same time. This allows for a richer understanding of conflict, such as that now occurring in Italy and Japan concerning debates of whether or not a person should have the right to be told his or her diagnosis (Gordon and Paci 1997;Interdisciplinary Group for Cancer Care Evaluation 1986;Swinbanks 1989;Reynolds 1989).

Gordon & Paci (1997) examine two prevalent cultural narratives, the 'social-embeddedness narrative' (dominant in Italy and Japan) and the 'autonomy-control narrative' (dominant in the USA). They claim the tendency to see disclosure as dangerous for the patient, versus seeing disclosure as a fundamental human right fit into two wider social practices, which are "taken for granted, and invisible, operating in the background of attention" (Gordon & Paci, 1997: 1434).

In the social embeddedness narrative, context is very important, particularly the context of family and hierarchical relationships. People, things and words are context dependent and derive their meanings from context. Relationships, being socially embedded count for more than individuality does. There will always be others (parents, elders, God, etc.) who should be turned to in situations of trouble or illness and who share the responsibility for taking care of you. Thus it is not necessarily important that the patient does not know their diagnosis, as long as the family and the physician do and are caring for and protecting the patient properly.

Misfortune, such as illness and death, are seen as capricious and outside of individual and even human control. An ideal state in which to deal with such misfortune is that of serenity or tranquility. It is more important to accept such events than to see them as a problem to be solved. Controlling one's destiny and in turn, having choice, are not ultimate values within this cultural narrative.

From the non-disclosing perspective of the social-embeddedness narrative, the American, or autonomy-control narrative approach looks harsh, irresponsible, lonely, and naïve. It looks as if, at the time the patient most needs to rest, be cared for, and protected by others, s/he has tremendous responsibility and work to do: to understand the diagnosis, decide on what therapy to follow, work at therapy, have a positive attitude, and plan 'rationally' for one's future end. Knowing looks very courageous, or foolish, or dangerous and seems to cause unnecessary suffering.

The autonomy-control narrative, dominant in the USA, is associated with various biomedical protocols such as open disclosure, informed consent, and the Patient Self-Determination Act. The individual is sovereign here. Autonomy and self determination are considered primary universal values and the rights of each individual being. Choice is inherently good and fundamental to self determination. In order for choice to occur, knowledge is essential as it creates options. Life, being materialistic, is infinitely knowable and controllable, and there is a bias toward action in situations of trouble.

Information itself is considered to be more or less autonomous from context and relationships. Explicit communication is distinctly preferred. First, talking or labelling something seems to help control a problem or danger, while keeping emotions "in" and non-clarity are seen as destructive. Second, explicit communication serves as a basis for equality, awareness of options, choice, and self determination, which are valued in the context of a physician-patient relationship.

From the perspective of the autonomy-control narrative, non disclosure looks like a grotesque denial of human rights, the right to information and control over one's life, body and death. The physician and family in such a case appear coercive, oppressive, and paternalistic.

Del Vecchio Good, et al. (1990) have also pointed out that a culture's oncology practices are also affected by the political economy surrounding cancer. For instance, in the USA, these researchers claim that the funding of cancer research, and widespread appeals for funding and screening promotion both depend on, and promote a vision of, cancer as curable. This makes the concept of hope especially potent, both in the individual's case, fighting cancer to achieve remission and health, and in the public's mind in general, that cancer research will find a cure. They also note that considerable importance is placed on the belief of the importance of thought and the emphasis on 'will' to help change the course of the disease in the body.

> If one has enough hope, one may will a change in the course of the disease in the body – [this] articulates fundamental American notions about personhood, individual autonomy, and the power of thought (good and bad) to shape life course and bodily functioning (Del Vecchio Good, et al., 1990: 61).

The experience of an illness and its causes can be powerfully culturally shaped. How do North Americans think cancer is caused and what can be done about it? How is desire to face things, gain knowledge of them, and then take action expressed?

### *Cancer Causes and Prevention*

> In global terms, the greatest impact to reduce the burden of cancer would be from the control of tobacco smoking and the control of breast cancer. Whilst tobacco control could be achieved by government and societal actions, prospects for the prevention of breast cancer are more remote (Boyle, 1997: sII26).

An estimated 19,200 women are expected to be diagnosed with breast cancer and 5,500 are expected to die of it in the year in 2000 in Canada (National Cancer Institute of Canada 2000a). 2,500 women are expected to develop ovarian cancer and 1,500 are expected to die of it in the year 2000 in Canada (National Cancer Institute of Canada 2000a).

Pritchard (1997) sums up most of the medical literature when she states that attempts to link breast cancer incidence rates to diet, particularly calories consumed as fat have not shown a strong correlation. Attempts to link breast cancer with non-fat components of diet, with exercise, or with other potentially controllable factors remains speculative. What we fall back on then, is that women who experience early menarche and late menopause, who have few interruptions in the menstrual cycle for pregnancy or breast feeding, and who have such interruptions late in life are at higher risk of getting breast cancer (Pritchard 1997). Pritchard (1997), as in much of the other medical literature, does not speculate on why these epidemiological patterns occur, except for a quick note that in women with certain genetic changes affecting acetylation of aromatic amines (a carcinogen), smoking may contribute to the development of breast cancer. Otherwise she notes that, "In an environment where prevention and maintenance are the watchwords of individual and group approaches to health, there are few levers to manipulate for primary prevention of breast cancer" (Pritchard, 1997: sI24). Ovarian cancer, being less common, is discussed less often, except for its connection with increased genetic susceptibility.

The discussion in Pritchard (1997), as in many other articles in the medical literature, moves on from primary prevention (the prevention of cancer incidence, or new cases of cancer) to "secondary prevention" or attempts through screening for cancer to detect it as early as possible and thereby prevent mortality. Options for screening for breast cancer include mammography, breast self exam, and clinical examination by a physician. Ovarian cancer screening methods are less well established, the current possibilities are transvaginal ultrasound or a CA125 test (a blood test detecting an elevated serum CA-125 level which occurs in a majority of ovarian cancers). The optimum frequency of screening is unknown (Burke et al. 1997)

None of these methods is perfect, which is why using several of them is usually recommended. For instance, mammography, while one of the few measures suggested to have reduced mortality within the general population over 50 in randomized studies is also less sensitive at detecting cancer in younger women (Elwood 1999). Questions about screening efficacy are particularly pertinent for women with a genetic susceptibility, as it is unknown if regular screening methods for the general population are as effective. In addition, it has been questioned whether women with a genetic predisposition to cancer may be more sensitive to radiation from mammography. Elwood (Elwood 1999), in a review of breast and ovarian cancer susceptibility testing and interventions for those at a higher risk in Canada, suggests that for those with a BRCA1 or 2 mutation, the benefits of many of these recommendations has not been established by clinical epidemiology and are based only on expert opinion.

Prophylactic oophorectomy or prophylactic mastectomy (removal of healthy ovaries or breasts respectively), has also been suggested to prevent cancer. The relative benefits and risks of such surgery is still undetermined, although a reduction in the incidence rate of breast cancer of 90% with prophylactic mastectomy has been proposed, and models have been used to try to determine increases to life expectancy (Hartmann et al. 1999;Schrag et al. 1997). While removal of the organ should prevent cancer from occurring, breast cancer has been documented in women afterwards, since residual breast tissue remains and breast tissue also occurs at other sites (Elwood 1999). There are also non-cancer-related side effects of prophylactic surgery, such as sexual and psychological effects with the case of breast removal and early menopause and reproductive consequences with ovarian removal. There are some strong emotional currents surrounding prophylactic mastectomies, particularly since there has been some advocacy associated with breast cancer to provide less invasive therapy alternatives to mastectomies. In addition, surgical reconstruction of the breasts is often performed along with a prophylactic mastectomy, accompanied by the current controversy in the media and elsewhere about the safety of breast implants. The statement of the French National Ad Hoc Committee (Eisinger et al. 1998) on prophylactic surgery is an example of some of the ambivalence that is associated with prophylactic mastectomy:

> Prophylactic surgery is in fact a mutilation. This procedure should be envisaged only on medical grounds. The patient's agreement is necessary but is not a sufficiently strong reason for operating. Nevertheless, in situations where no chemopreventive procedures are adopted, using only screening strategies means allowing about 80% of the women screened to develop breast cancer, and almost 20% of them to die of cancer. This figure takes into account the 30% decrease in mortality which can be expected to occur as the result of mammographic screening. Although prophylactic mastectomy is never recommended, it may sometimes be envisaged (Eisinger et al. 1998: 946).

Although the North American medical consensus is usually less negative towards prophylactic surgeries, they still urge caution, given the possible side effects and the unknown efficacy of the surgery (Burke et al. 1997;Elwood 1999;Haid and Lembersky 1998).

Chemoprevention has also been suggested to prevent cancer among mutation carriers. The use of tamoxifen, for example, has been suggested. However, its efficacy for healthy women in preventing cancer (as opposed to preventing a reoccurrence in the short term) is yet to be established, nor have side effects been adequately characterized (Elwood 1999). No other chemopreventive agents have yet reached the stage of clinical randomized trials. One suggestion is that cytotoxic agents (either chemical or biological) be injected directly through the nipple and into the ducts to kill epithelial cells, which line the breast ducts and which are the source of the majority of breast cancers. It is estimated that total destruction of the epithelial cells in the breast should prevent at least 95% of breast cancers, which should theoretically eliminate risk of cancer while preserving the outward appearance of the breast (Sukumar and McKenzie 1996)

In contrast to the medical literature, which remains unconvinced on the matter of lifestyle and environmental agents, the popular press does mention many lifestyle related issues (focusing on tobacco, diet, exercise and workplace carcinogens) that could be avoided in order for people to prevent cancer (Willett et al. 1996;Trichopoulos et al. 1996). In these articles cancer in general is discussed, but breast cancer is often assumed to fall into the same category. Some argue that environmental influences, particularly environmental chemicals, on cancer risk are not given enough attention in trying to prevent cancer (Steingraber 1998;Davis et al. 1997;Panter 1996). Steingraber (Steingraber 1998) in particular, suggests that lifestyle and diet are not separable from environmental factors, and that focus on lifestyle, or even genetics, could sidetrack us from exposure to harmful chemicals.

> Cancer incidence rates are not rising because we are suddenly sprouting new cancer genes. Rare, heritable genes that predispose their hosts to cancer by creating special susceptibilities to the effects of carcinogens have undoubtedly been with us for a long time. The ill effects of some of these genes might well be diminished by lowering the burden of environmental carcinogens to which we are all exposed. The inheritance of a defective carcinogen-detoxifying gene would matter less in a culture that did not tolerate carcinogens in air, food, and water. By contrast, we cannot change our ancestors (Steingraber, 1998: 260).

The lack of desire to focus on environmental causes of cancer could be due in part to the complexity of proving that such a link exists, particularly as low level doses over a long time, as well as the variety of chemicals present in the environment, make it hard to clearly ascertain causes linked to environmental factors (Steingraber 1998).

### *Genetic Testing and Society*

Individuals working in this field (in BC and elsewhere) claim that genetic research and testing has the potential to provide the ultimate in preventive medicine. Individuals at high risk can be identified and can change their lifestyles to lower their risk (Lippman 1992;Litwin 1998). It can also release some from worry about family trends (Litwin 1998). In addition, this research is seen as increasing the knowledge about: a) the genetic basis of cancer; b) changes that take place at a molecular level; c) how tumour suppressor genes function; and d) other information that will eventually help the general population who suffer from sporadic cancer (Litwin 1998;Perera 1996;Cavenee and White 1995). Scientifically, these processes may be easier to understand in a small population with a higher risk and the findings can then be extrapolated to the wider population. Certainly, many people in BC are interested in acquiring genetic information about themselves and their families (Litwin 1998).

However, at the same time, some social scientists are questioning if intensive genetic studies are truly the best way to provide better health for the majority of people (Nelkin and Lindee 1995;Lippman 1992). There are questions about whether identifying genetically susceptible people will merely lead to insurance and employment discrimination. For example, in a study of the perceptions of 332 members of genetic support groups in the United States, 25% believed they were refused life insurance, 22% believed they were refused health insurance, and 13% believed they were denied or let go from a job due to a genetic condition, carrier status, family history, or genetic testing (Lapham et al. 1996). Confidentiality of this information is certainly a major concern within the medical literature (Groopman 1998).

The question of who controls these technologies and who will benefit from their use is raised. Will as Lippman (1992) asks, the pharmaceutical companies who profit by marketing testing kits that make patients out of the healthy see the primary benefits? Will workplace genetic screening for employees protect them from hazardous workplaces? Or will workplace genetic screening protect just the employers from liability? (Draper 1991).

There are also concerns that a focus on genetics in medicine as a cause of ill health will redefine how we conceptualize disease causes and shift the responsibility for health away from society to the individual, ignoring structural threats to good health (Lippman 1992;Nelkin and Lindee 1995). This is particularly true where diagnosis of a genetic susceptibility is intended to lead to lifestyle changes in order to prevent the disease. Some individuals are better situated financially to make lifestyle changes than others. There is some fear the expectation of individual management of health will lead to blaming the patient who gets ill because he or she did not follow prevention strategies.

> Disease does not result simply from individual failure to follow advice. Does a single mother with at least a double work load have the 'leisure time' for the exercise that might reduce her chances of developing osteoporosis later in life? Can a black woman constantly encountering racist practices reduce her stress by resting? As suggested above, conditions of society such as poverty, racial bias, gender discrimination and lack of political power, are among the well-documented non-genetic risks to health that create 'susceptibilities'. Why not call *these* factors 'markers' and label them for intervention? (Lippman 1992:1473).

As Nelkin & Lindee (1995) point out, beliefs about blame and responsibility have social policy consequences.

Accompanying these consequences is the possibility that prenatal genetic testing for susceptibility to late onset conditions such as cancer will be requested (Carter and Hailey 1999). Generally, prenatal testing is more readily accepted, by both society and the medical community, for diseases (such as Tay-Sachs or Down's Syndrome) that appear in childhood and are untreatable. With a late onset disease (such as with breast and ovarian cancer) where prevention and treatment options are available, it is reasonable to predict that prenatal testing will be less frequent (Carter and Hailey 1999).

Browner and Press (1995) argue that American society shows a growing tendency to see human behaviors through a "prism of heritability", with genetics as the source of human weakness and limitations. Nelkin & Lindee (1995) describe the tremendous pervasiveness of the concept of the gene in popular culture and point out that biological explanations often appear to be more objective and less ambiguous than environmental or social ones. This could be part of the reason why the gene is used so readily as a North American cultural concept, and narratives of genetic essentialism are used to explain evil, to predict destiny, and to justify institutional decisions in popular culture. They continue to say, "Infused with cultural meanings, the gene has become a resource that is too readily appropriated, too seldom criticized, and too frequently misused in the service of narrow or socially destructive ends" (Nelkin and Lindee 1995: 199).

Despite the popularity of the gene, there is controversy concerning how the public perceives genetic testing. Jallinoja, et al. (1998) have pointed out the importance of contradiction in people's opinion on genetic testing. Indeed, people's attitudes towards many aspects of modern technology are often ambivalent (Nelkin 1984;Giddens 1991;Jallinoja et al. 1998). Jallinoja et al. (1998) suggest that technologies provided by science in modern times may be especially problematic, since they are provided without a moral framework in which to use them. Contradictory attitudes can therefore reflect people's "efforts to balance the pros and cons of genetic testing and to find the borders of acceptable conduct" (Jallinoja, et al., 1998: 1372). Jallinoja, et al. (1998) suggest that it is important that "instead of forcing clients to reach attitudes and feelings free from conflict [health professionals] help their clients to cope with contradictory feelings and help them find an acceptable solution for their specific life situations" (Jallinoja, et. al., 1998: 1372). This brings us to the specific context of how individuals going through genetic testing incorporate these contradictions and how genetic testing affects their lives.

## *Genetic Testing and the Individual*

### Psychological Effects

There has been considerable concern over how people decide to be tested, what psychological effects genetic testing for cancer susceptibility will have on individuals, and how well they interpret and understand their risk. Many genetic counselling and psychological studies have been undertaken to ensure that those being tested will receive proper care. In addition, a popular guide to going through the genetic test in Canada has been written (Sharpe 1997).

Women's reasons for being tested vary. In a US study, researchers found individuals receiving test results were more likely to be those who already had health insurance (Lerman et al. 1996). A study in Canada (including BC) suggested the women who choose to have the test may believe the potential costs of using this new genetic technology to be relatively few and the authors underline the role of genetic counsellors to ensure the provision of balanced and complete information to those being tested (Cappelli et al. 1999). Studies to date suggest that the main reasons stated for having the test are to help research, to clarify the risk of cancer for one's children, and concern about surveillance and prevention (DudokdeWit et al. 1997;Lynch et al. 1997). As for not participating, researchers in one study in the US found that fear of insurance discrimination was one of the chief reasons for refusing test results (Lynch et al. 1999).

Researchers have commented that it was essential that those who undergo testing receive appropriate counselling to ensure that test participants understand the results, and to deal with the emotions that accompany test results (Lynch et al. 1999;Lynch et al.

1997;Lynch et al. 1997;Lynch et al. 1997;Croyle et al. 1997;Croyle et al. 1997;Croyle et al. 1997). Psychosocial researchers suggest that participants who are tested in research-based protocols in which they receive thorough counselling and education, are for the most part, not likely to experience significant psychological distress in the long term (Croyle et al. 1997). Indeed, there is some suggestion that those who refuse testing and who have a high level of cancer-related stress are more likely to experience depression than those who are tested (Lerman et al. 1998). This is paralleled by a study in which researchers found increased distress among those who refused to receive the results from Huntington's disease carrier testing, compared to those who had received their results – either positive or negative (Wiggins et al. 1992). However, the risks of psychological distress, family disruption, and non-adherence to surveillance guidelines would probably be greater when testing occurs in a clinical setting without adequate education, counselling, and follow up (Croyle et al. 1997).

As yet, there has been little research on what patients' responses to test results are like when they receive different levels of counselling (Croyle et al. 1997). In addition, these results do not account for the short term distress, such as depression, confusion, persistent worries, and sleep disturbances, that has been observed directly after the disclosure of test results for those who carry a genetic mutation (Lynch et al. 1993).

### Men and the Psychological Effects of Testing

The main focus in genetic testing for BRCA1 has been on at-risk women, not only for most professionals involved, but also for the men of high risk families (DudokdeWit et al. 1997) (Struewing et al. 1993). Men in high risk families tend to focus on their female relatives and their risks (life and death) and thereby see the testing of themselves as of lesser significance. However, DudokdeWit (1997) notes that it is important to keep in mind that men are deeply affected psychologically when their female relatives are at risk. This is in addition to any worry they may have over their own increased risks of prostate and colon cancer, for a BRCA1 or BRCA2, or an increased risk of breast cancer in the case of a BRCA2 mutation.

## Risk Perception and Embodied Knowledge

Accompanying the questions about the psychological effects of testing are questions about how individuals will perceive their risk of breast or ovarian cancer and how they will act on that perception. There is some concern that assessing disease risks by DNA analysis may result in a sense of fatalism, and adversely affect motivation to change behaviour and to reduce risks. In a study on parents' perception of inherited hypercholesterolaemia researchers suggest that when parents perceived the test as detecting raised cholesterol, the condition was perceived as familiar, dietary in origin and less threatening. However, when the test was seen as detecting a genetic problem the condition was perceived as uncontrollable and therefore more threatening (Senior et al. 1999).

Individuals who are tested for hereditary breast and ovarian cancer appear to overestimate rather than underestimate their risks prior to receiving results (Lynch et al. 1999;Hallowell et al. 1998). Watson, et al. (1998), in a study of how women in the UK receiving counselling (but not test results) about family risk of breast cancer found that 41% of women accurately recalled their personal risk of breast cancer at a one month follow up. 25% overestimated, 11% underestimated, and 23% could not remember or did not know their breast cancer risk. Furthermore, these researchers suggest that having a precise risk figure may be less important to women with a family history of breast cancer than taking away an impression that something can be offered to help them manage that risk (Watson et al. 1998). These findings correspond with those of other researchers who found recollection of exact numerical risk was poor after counselling in situations with or without test results (Stadler and Mulvihill 1998;Hallowell et al. 1998;Evans et al. 1993;Peshkin and Lerman 1999). This may indicate that individuals see their risk not in terms of numerical probability, but either qualitatively, as more or less than the general population, or in absolute terms (that they either will or will not get something) (Hallowell et al. 1998).

Risk perception is difficult to measure precisely, particularly since cognitive processes and weighted information are only part of making complex health related decisions that also include emotions and social processes. Quantitative surveys (asking subjects to give a numerical estimation) can fail to include many details about how an individual is creating his or her own risk perception (Fischhoff et al. 1993). Fischhoff et al. (1993) comment that studies often reveal that risk perceptions are decreased by a sense of invulnerability, or are increased by "availability bias", in which experience (either reported in the media or personal) will cause individuals to see some causes of death as more lethal or potentially risky than others. This bias may "reflect a general tendency to estimate the frequency of events by the ease with which they are remembered or imagined – while failing to realize what a fallible index such availability is" (Fischhoff et al. 1993: 187). Researchers have created models of people's intuitive theories of how risks accumulate, mostly in order to improve communication on quantitative probabilities and to identify and then 'correct' any misinformation within an individual's thought process on a specific risk (Fischhoff et al. 1993).

Teasing apart the cognitive factors at work in risk perception, while important, gives only a partial picture. Availability bias, or fearing something already experienced, can never be completely eliminated due to the fundamental effect that such bias can have on how one conceives of risk and makes subsequent decisions. This is especially true in the case of hereditary breast and ovarian cancer. It is important to understand such "bias" which results from personal experiences, since it will always be a part of a person's risk calculation.

Chalmers & Thompson (Chalmers and Thomson 1996) in examining women's breast cancer risk perception after a relative has had breast cancer, found the process of risk perception to be complex and multifaceted. This process changes with time, and exhibits different steps that individual women can choose to take along the way. They further note that family history as a risk factor for breast cancer is important beyond the epidemiological context, but has psychological and social dimensions as well. Since living with the cancer experience of the relative can have the emotional impact of a major life event, it requires much coping effort and can influence the ability to focus on one's own health needs (Chalmers and Thomson 1996).

Incorporation of personal experience into a sense of risk, as well as the ability of individuals to moderate medical information based on experience has been noted by other researchers. Rayna Rapp, for example, in studies of the use of and meaning surrounding amniocentesis testing, has found that women's estimates of risk will be affected by their own 'personal sense' of statistics (Rapp 1988). To professional couples for whom the 'risky' birth (birth over 35 year of age) is a first or second pregnancy, and who do not know a large number of children among their personal acquaintances, a risk of one in three hundred that their child could have a birth defect may sound like a high risk. However, the low income mother of four, who comes from a family of eight, and all her sisters and neighbors have had similar histories, has seen many babies born without recognizable birth defects. "To contrast these experiences with a number produced by a lady in a white coat proclaiming that the risk of a baby with a birth defect is steadily rising with each pregnancy requires a leap of faith in abstract reasoning" (Rapp 1998: 113). In addition, Rapp has documented women contesting or negotiating with genetic diagnoses that have an ambiguous clinical outcome from a genetic test (Rapp 1998).

Lippman, in a study on the decision to use amniocentesis, found that women routinely negotiate with biomedical knowledge (Lippman 1999). They then transform it and combine it with their own feelings, beliefs, and personal experiences in order to create an "embodied knowledge" on which to base their decision either to take or refuse prenatal testing (Lippman 1999). Lippman uses the term embodied knowledge to mean knowledge which

> resulted from various transformative, interpretive, and integrative processes in which women engaged to refashion "received" biomedical information, taking ownership of it and weaving it together with their own experiences and understandings and with "inside" information, their feelings and beliefs (Lippman, 1999: 259).

Embodied knowledge is a useful concept for trying to understand the way multiple sources of information, some 'clinical' and 'objective' and some derived from personal experience or others' stories are bound together to create a framework within which people can act and explain those actions to themselves and others. Lippman uses it in a different and more flexible context than it has been used by others, such as Gordon

(Gordon 1990), who refers to it as an unconscious knowing or a 'sensing'. Lippman (Lippman 1999) uses the term in a similar fashion to that in Browner & Press (Browner and Press 1996) in which embodied knowledge is categorized as subjective knowledge from a woman's perception of her body and its natural processes. However, Lippman expands the concept to include a woman's actual experiences as well as information from others over which she takes "ownership" (Lippman 1999).

A wider conception of embodied knowledge allows for the process of negotiation of information from a variety of sources, without framing it in a binary 'resistance/acceptance' context. Embodied knowledge also allows for an understanding of how knowledge gained from both the body and the mind can be seen on an equal footing, combined, and then used in future action, thereby 'embodying' the knowledge.

Lippman found that women deciding whether or not to use prenatal diagnosis would use four main processes to negotiate biomedical knowledge. They would personalize the meaning of maternal age, recalculate maternal age and its relation to Down's syndrome, redefine the meaning of 'fetal health', and use the information from the genetic counselling to confirm their own knowledge claims. For instance, with maternal age and Down's syndrome, some women claimed that, since everyone has some chance of having a child with Down's syndrome, their "increased" risk of doing so after age 35 was meaningless. They therefore negotiated the meaning of one piece of biomedical information using another and the malleability of probabilistic information facilitated such processes. Similarly, they could redefine the meaning of maternal age by citing lifestyle factors, such as being in better shape than most women their age, and thereby negate the significance of maternal age in their particular instance.

The redefinition of fetal health, could mean significance was placed on the bearing of a living child, rather than carrying a child with no genetic abnormalities, sometimes using ultrasound results as a justification for doing so. Alternately, information gained in genetic counselling can reinforce decisions that were already made. Women therefore turn authoritative, biomedical information into their own understandings of the likelihood and meaning of having a healthy child, which is what Lippman categorizes as a category of embodied knowledge. This component of transformed biomedical knowledge is interwoven with a woman's feelings and beliefs to form embodied knowledge as a whole (Lippman 1999). Information from all sources, then, both from biomedical sources and personal experiences, is woven into an internally consistent "embodied" knowledge. The particular embodied and contextualized knowledge of an individual woman at a particular time is what leads to a particular course of action, in Lippman's case (1999) the decision to use or not use amniocentesis.

> We need to acknowledge that women develop their own explanatory theories and apply them consistently, borrowing material from all over in so doing. In these complementary ways of knowing, women embrace multiple ways of knowing and doing to live their lives in which attachments to the self and to others are important (Lippman 1999: 272).

# Chapter 3: Research Methods

In this study, I explored issues and meanings surrounding genetic counselling, testing, and cancer risk for women who had gone through genetic counselling due to family histories of breast and/or ovarian cancer. I also hoped to help improve the communication on hereditary cancer topics by identifying where the women's understanding of certain subjects differs widely from that of medical professionals. I used a qualitative approach to allow an investigation of a variety of issues (as defined by the interviewees themselves) regarding the use of genetic testing as a technology. I further examined how knowledge, such as their perception of their own risk of contracting cancer is incorporated into individuals' daily lives, for instance by participation in preventive activities. Qualitative methods have repeatedly been found useful when seeking broader understanding of a human phenomenon, such as the meaning of illness, or perceptions and responses to risk factors (Lippman 1997;Denzin et al. 1994;Kvale 1996). The study design was based on an unpublished research proposal (Glickman et al. 1997).

Interviews were conducted in British Columbia, Canada in Victoria and Vancouver Island and in Vancouver and the Lower Mainland. Individuals were contacted through genetic counsellors in the Hereditary Cancer Program at Victoria General Hospital and the BC Cancer Agency (Vancouver Clinic). Ethical approval for the study was obtained from the Capital Health Region and the University of Victoria, for the Vancouver Island/Victoria interviews and from the BC Cancer Agency and the University of British Columbia for the Lower Mainland/Vancouver interviews. Permission to mail a letter informing individuals about the study was obtained, the letter was sent, and then a follow up phone call determined whether the individual was willing to participate in an interview. Interviews took place at a location of mutual convenience, usually the home of the participant or the interviewer. Written consent, both to make an audio recording and use the interview for the purpose of describing general trends was obtained from the research participants. Separate written permission for direct quotes to be used was also obtained (see Appendix B: Letters of Consent). Interviews were tape recorded, and transcribed verbatim.

There was only one interview session with each individual. There would have been additional advantages to a second interview session, where I returned the interview transcript and reviewed the main analytical points of the research with the participant as this would have insured additional validity. However, the drawn out interview period, spread from the summer of 1998 to the spring of 1999, as well as the accompanying lengthy transcription time made this difficult. In addition, I was reluctant to pursue this as the research benefits had to be weighed against the inconvenience to the women of meeting me again, particularly since many of them were involved in at least one other research project to do with evaluating the genetic counselling and testing for BRCA1. Saturation was reached in the interviews, in the sense that similar themes and opinions were mentioned repeatedly by a number of individuals.

Interviews were qualitative, with open ended questions. They lasted approximately one to two hours. All interviews were in English and I began by asking for personal background. I then proceeded with general questions about how the individual had become involved in genetic counselling, including information about family experience with cancer. Finally, I asked specific questions about a range of topics if they had not come up previously. Specific issues of interest were interviewee's opinions on genetic counselling and testing, their risk of developing breast and/or ovarian cancer, genetics, screening practices, and lifestyle influences (see Appendix A: Interview Protocol). This approach to the interviews was intended to allow issues of importance to the interviewees to be raised and explored.

While the interviews generally began with women's narratives about how they became involved in genetic counselling and testing, interview style questions later in the interview allowed the wide range of issues I was interested in to be covered. I chose to do interviews over focus groups or some other method of qualitative investigation because they allowed pertinent issues to be explored in a private setting which allowed confidentiality to be maintained. They were also an appropriate method to better understand the variability of how individual's understood and incorporated genetic testing into their lives, rather than ascertaining a group consensus. Interviews therefore better fit the research situation and goals.

I analyzed interview texts for content using the computer software, QSR NUD*IST[1] for text-based analysis. I focused on the description and interpretation of themes and differences that arose from the interviews on topics of genetic counselling, genetic testing, risk, and prevention. The tree structure of NUD*IST allowed me to examine several issues that came up in the conversations in detail as well as facilitating examination of those issues within the three risk groups present in my interview sample. One of the disadvantages to using NUD*IST is that it can separate comments on a particular issue from the context of the conversation in which it occurred. However, doing the interviews and transcription myself, reduced this methodological difficulty, since it was easier to remember the interview context. The use of this program to do analysis might have been less useful if I was focussing on a narrative approach rather than on issues.

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[1] Distributed by Scolari.

## Interviewees

Twenty-six people were interviewed in 21 interviews (some family members were interviewed together at their request). Predominantly women, but three men who were tested for BRCA1 mutations, were interviewed. This reflects the current gender bias in genetic testing for BRCA1 mutations, probably due to a woman's greater risk of developing breast or ovarian cancer when carrying a BRCA1 mutation. Only about 1-2% of those currently being tested for BRCA1 mutations are male (M. Micek, pers. com.).

The women interviewed were predominantly Caucasian, anglophone Canadians. Ethnicity was not specifically questioned. Only one woman did not speak English as a first language. Ages ranged from the 20's to 60's, but were predominantly between 35 and 55. Educational levels ranged from high school completion to a graduate degree, and interviewees were involved in a wide range of occupations. Most of those interviewed were lived in Greater Victoria in the Capital Regional District (11) or the urban area of the lower mainland surrounding Vancouver (10), but a few were in outlying areas surrounding those urban centres or in other smaller cities or towns on Vancouver Island (5).

Table 2: Location, Test Status and Gender of those interviewed.

| Location & Gender | Positive Result | Negative Result | Ineligible | Total |
|---|---|---|---|---|
| Vancouver Island Men | 1 | 2 | 0 | 3 |
| Vancouver Island Women | 4 | 3 | 6 | 13 |
| Lower Mainland Women | 5 | 2 | 3 | 10 |
| Total | 10 | 7 | 9 | 26 |

Three groups of individuals were interviewed from Vancouver Island (Victoria primarily) and Vancouver and the Lower Mainland (Table 2). The first group (10 individuals) involved those who had tested positive for a BRCA1 mutation, and therefore had a higher risk of breast or ovarian cancer. Only two of these ten had actually developed breast cancer and none had ovarian cancer. The second group (7 individuals) had also been tested for a known gene mutation in their family, but were shown not to have a BRCA1 mutation. Before testing these individuals were likely to be at 50% risk of inheriting a mutation. Due to testing negative for the family mutation, they therefore had the same risks of developing cancer as other Canadian woman their age. The third group (9 individuals) had a strong family history of breast or ovarian cancer, but could not participate in testing because they lacked a living family member, who had previously developed breast or ovarian cancer, who was willing and able to participate in testing to identify a potential familial mutation. The three groups were therefore similar in that all had a strong family history of breast and/or ovarian cancer, but differed in whether or not testing was available to them and the outcome of the test.

# Chapter 4: Findings

The findings are organized into three main sections according to the goals of the study. In the first I explore the individual interaction with genetic counselling, addressing the perceived quality of the communication between interviewees and genetic counsellors. Since few large problems emerged concerning genetic counselling, in this section I focus on what participants felt was most important about genetic counselling, centering on the topics of information, medical access, and emotional support. I then review the few problems and some suggestions that arose about the genetic counselling protocol.

In the second section, I review the opinions of participants about genetic testing. The general tone of the interviews reflected a very positive attitude towards genetic testing, but not without knowledge of some of the attendant disadvantages. I found the benefits and disadvantages of testing, as perceived by those actually tested, are weighed, with the benefits seen as being substantially higher than the disadvantages. At least for the present. I then review the views of those who were unable to have testing, and identify themes of advice that would be given to others thinking of undergoing testing.

Counselling and testing are interconnected as part of a single process in the minds of those interviewed. The separation here is somewhat artificial. Questions specifically about counselling were often answered with comments about the test. It is important to note that the counselling component of the experience had a substantial effect on how they interacted with the testing itself, and vice versa. However, it is useful to look at what people felt they were getting from genetic counselling, as well as genetic testing.

In the third section, on risk perception and action, I look at how individuals in the three different risk groups view their risks and what actions (usually medical) are necessary for lowering them. Because the three groups tend to hold separate views, I discuss them separately. I close by examining the various views on cancer prevention and their hopes for future developments in cancer prevention and cures.

Throughout all of these sections run themes about the importance of information, knowledge, and control in the genetic counselling and testing experience. These themes appear over and over again in the quotes in all three of the sections, although the importance of information in the context of genetic counselling is dealt with directly in the first section. These overlapping and reoccurring themes are important, since they help to illuminate the cultural meaning of genetic testing as an experience as well as a technology.

Quotes from the interviews are all given with code names in place of real names, in an effort to preserve confidentiality and anonymity. In addition to the code name, test result, and where applicable, family relationships are given. Quotes have also been slightly edited from the original verbal transcript to better suit written conventions.

## Genetic Counselling

On the whole, almost all of those interviewed were satisfied with the genetic counselling (85%). A further few (approximately 7%) were neutral, expressing little opinion. Only a small percentage (approximately 7%) had not felt good about their experience with the counsellor. However, several of the majority who perceived counselling as a positive experience did have certain reservations about counselling or suggestions on how to improve it.

Participants' positive experiences with genetic counselling focused around their interpersonal interaction with the counsellor and on her abilities to communicate complicated ideas and make them feel comfortable. The counsellors (and other staff who sometimes accompanied them, such as a nurse or geneticist) presented information well. They were understandable and the clear language and pictures used to help explain concepts were valued. The counsellors took the time to answer questions, and were very thorough. Above all, meeting with the counsellor was an experience with which almost everyone felt comfortable: Their concerns were addressed and questions answered. A sense of control in the genetic counselling context and feeling free to discuss desired topics was appreciated.

> *Ms. G (ineligible): She was very, you know, understandable and what you didn't understand, she could explain, which was good. Because it is such an abstract kind of thought, you know? So, yeah, I came out of it feeling good. I didn't come out of it feeling confused.*
>
> *Ms. N (positive): And she was very gentle, and positive, and yet very informational, and I think we all came out recognizing the importance of the decisions that we had to make on it. And that, by the decisions we made, we would either be ignoring it or having to act on it.*
>
> *R (researcher): Would you have liked anything to be different?*

> *Ms. F (negative): No, no because even if I would have liked something to be different, I never felt that I wasn't, sort of, in control of what was happening. By that, I don't mean [the genetic counsellor] had no control over what was happening, but I didn't feel I was going into a position where I wasn't able to express what I wanted to say, or discuss what I wanted to discuss, okay?*

There were three main patterns that appeared in the interviews regarding genetic counselling. The most prominent dealt with the information or knowledge that women were taking away from the counselling experience. The second concerned referrals or greater access to medical services through the counselling and testing process. Finally, discussions about the importance of the emotional and social benefits of counselling were common. Reservations about genetic counselling were also mentioned.

### ***Information Provided by Genetic Counselling***

The benefits of knowledge gained from counselling sessions were intertwined with information gained from testing. Counselling mediated this information and provided the context in which decisions were made about whether or not to acquire the information genetic testing could provide. Beyond test results, women refer to knowledge and information when discussing risk factors and how the science behind the test worked.

> *[Ms. O & Ms. N (sisters, both positive)]*
> *Ms .O: As time has gone on, I find that I, the way I look at it is a little bit different from a year ago, what I felt about it. Yeah, it's really, you know, the information, as you feed on more information, the more you see your doctors and everything, the more secure you feel in it. You realize it's a real blessing rather than...*
>
> *Ms. N: Knowledge is power and I just felt that that's what it's been for us.*

Several women were interested in learning the genetic basis of cancer heritability and what was involved in being part of the cancer research program.

> *Ms. D (ineligible): I didn't really understand the makeup of the cells that... Like the way that she had it drawn out for us was really good and I had no idea before about the names of the genes or exactly what it was that was passed down for genetics. And so, I found that was really interesting. I thought, I learned a lot from that.*

The counsellor's ability to provide additional information and answer questions was highly valued.

> *Ms. O (positive): Yes, she's willing to look into it for you and she sends material. If you ask any questions of her, she goes, you know, I think I've read an article, and it's in the mail within two or three days. She's just fabulous. And those kinds of things are really exciting, you know, when you do have questions to have somebody that has got the knowledge behind them to give you it, you know?*

Some women found that even though they enjoyed receiving information, they later realized they did not need to retain it all. Those who tested negative or who could not be tested mentioned that they would have wanted to know more if they had tested positive, or if they could have been tested. Many were given more information than they had expected, but this was beneficial. Putting an estimated value on risk, perhaps discovering the likelihood was lower than expected, and generally finding out more specifics about risk were encouraging. This information was a beginning, not an end to the issue. Knowledge of future research and hope of a cure were important as well.

> *R (researcher): The other part of that question was the information that you were hoping to get, how did that compare to what you actually got in the session?*
> *Ms. A (ineligible): Oh, it was even more than I had anticipated or hoped for. For me it was good news. To hear that we're not in the more than 50%, like 65%, you know, we have a 65% chance of . . . or higher, is what we've been hearing for years and years and years and it's really not. I think that's what I got, ultimately, out of it.*

> *R: So, what would you say was the most helpful thing that you got out of the appointment?*
> *Ms. J (ineligible): The numbers. Just, the chances of getting it decreasing and all, let's see, with that appointment it's just that. Yeah, the numbers and*

> *just all the work that's being done right now and, you know, you feel like you're really going somewhere.*
> *R: In what sense?*
> *Ms. J: Going some where, as far as, it's not a dead end issue. You know, there's stuff being worked on all the time with it.*

Risk figures were always important, but became paramount to those who received a positive test result. Discovering the mutation and the associated higher susceptibility prompted a greater focus on what the statistical risks meant to the individual woman, particularly in reference to screening, prophylactic mastectomy/oopherectomy, and lifestyle factors. At this point, the information previously received from the counsellor needed to be re-evaluated and expanded so a woman felt comfortable making a choice about her health. Counselling was very useful in this process by giving additional information, or clarifying information already given.

> *Ms. Y (positive): ...I guess it was a little bit of a misunderstanding. I understood it that if you had the mutated gene, they couldn't tell you when it would cause the other one to mutate. So, basically, yes you are going to end up with breast cancer or ovarian cancer, but we can't tell you when. That's how I understood it. And it wasn't until we went back and got the results, but then they said, no. You could die an old lady before it causes the other one, ever, to mutate. So, then it was like, oh, well, okay. Hell, I could get hit by a bus before anything ever changed. So, it wasn't a big deal.*
> *Like I said, I had that misconception that if I had the gene, that was it, and I was like, okay, let's cut everything off and be done and not worry about it. And then I found out, well no, you still could get it, because they can't remove everything and so ... I found the counselling sessions to be helpful in the information that I got.*
> *R: Just in terms of clearing up misconceptions, or?*
> *Ms. Y: Yep. Myths, too. Things that you assume. And stuff that you hear over time. When I was, sort of, coming of age, it was, being on the pill for too long causes ovarian cancer. And now they find out it actually doesn't ... But if I hadn't had that information from the counselling, then I could have made, I don't want to say drastic, decisions, but I would have. Which now I'm glad that I didn't.*

### *Gateway Access to Medical Services*

Genetic counselling was also valued since it provided referrals and important information about medical services that would help support women in reducing their likelihood of developing or dying from breast or ovarian cancer. For instance, counsellors could help facilitate access to oncologists for screening. Medical access was linked to information for many. They were interested in finding out more about hereditary cancer and what they could do about prevention.

> *R: What did you find most helpful about it?*
> *Ms. D (ineligible): Knowledge, the fact that she did write it out. She did show us exactly what her knowledge of what happens and the fact that she offered us some support in the fact that she said there's a new clinic opening up in Vancouver and another avenue for us. So, rather than leaving us in a complete dead end, she's given us another path to follow.*

### *Emotional and Social Benefits of Counselling*

A third important component to the genetic counselling sessions as seen by the interviewees, was the combination of emotional and scientific support. This was useful for making concrete decisions about testing and medical issues. It also helped people prepare for the emotional or social issues surrounding genetic testing for cancer susceptibility. These issues included control of fear through a sense of objectivity, warnings about possible consequences of being tested (e.g. insurance loss), and help deciding whom to tell about the testing.

> *Ms. F (negative): It is important, I think, to have an objective avenue, because there's so much of the emotional that comes with this, so much emotional baggage, which comes with these fears, and you need the objective point of view. Sort of, at least dull the edges.*
> *I think one thing you have to recognize when you go into a counselling situation, usually you're going in with a lot of preconceived ideas, a lot of anxieties, probably some emotional baggage from whatever. You're going in with a very subjective, emotional point of view and she has to be objective and go through everything and then come back with an objective*

> *answer, which will help you make decisions in the future. So, when you go in, really, you're just dumping everything and I mean you go back and you're hoping for, sort of a bedrock of, not a bedrock, but at least a foundation of information on which you can then make future decisions. But depending on your state of mind in the following sessions, you may not give a lot back, especially if you get the information that yes you do carry the gene or whatever.*
>
> *What you're really doing is you're sharing your fears with someone that's qualified to look at them and that is actually a great help. And it isn't a medical doctor, or whatever. This is someone with a different perspective. Because you're going to bring to this much more than you bring to a session with a physician. You know, with a physician you're sort of throwing your pound of flesh on the examining table and that's really quick, you just get ... But when you're seeing someone like [the genetic counsellor], you're bringing everything out.*

> *Ms. K (ineligible): Before the counselling session, I had just a fear, or I had just a, you know it was like, I may get it, you know? Now I have an educated guess that I might get it, but I may not. And I know, I can see now in my head the reasons and the, you know, it's like this, it's more ... Before it was all the books piled up on the floor and now the books are all in the shelves nicely, you know? And it looks neat that way there, so. I don't think that I have less chances or more chances of getting it, I just understand it more now. It actually doesn't scare me as much as it used to. Before it was just like, [in-drawn breath], it's something that I had no control over. Now, I find, it's as if I went to get some control about it. Not about getting it or not getting it, but about going to get information. What can I do? So, it's as if I've taken a certain kind of ownership or control over it, in a certain way.*

Since hereditary cancer does not simply affect individuals, but entire families, genetic counselling provided assistance with informing family members about the possibility of being tested.

> *[Ms. N and Mr. X, both positive, daughter and father]*
>
> *Ms. N: I think, another part of it, too, was, once I realized there was a hereditary thing, not only just for our own children and our grandchildren, my mind all of a sudden, started going, my cousins... My uncles and aunts ... And, right away, I phoned [the genetic counsellor] and how can you get in touch with them? That was one of the things I wanted to know was how could she talk to them? And I realized the shock element that was involved in finding out. And I wondered, if [the genetic counsellor] could do it herself, it would probably help a lot, but I know she can't be everywhere.*
>
> *Mr. X: Well, she gave me a letter, to take to my relatives.*

Going through all the consequences of testing was considered very valuable, particularly things one might not otherwise consider, such as insurance.

> *Ms. X (positive): And [the genetic counsellor] actually sat down and she, for a good hour, told us of all the consequences of finding out. All the consequences of not finding out. And she just, put a plate of reality in front of you.*
>
> *Ms. W (positive): Because when you hear you're going to the Cancer Agency, it's like, oh, people hear about it and, you know, one thing they tell you about is the insurance. Something that you would never think about, you know? Like, you may have to give that information; do you want to do stuff before you go through the testing? Very knowledgeable.*

While some mentioned that they did not require much of the counselling support, they still appreciated that it was there to turn to if they did need it in the future. Others felt that the emotional support was a very important aspect of the genetic testing process.

> *[Ms .W and Ms. X, both positive, mother and daughter, respectively]*
> *Ms. W: And then, you went for the test, came back ... I don't know if I'm just abrupt or fast or whatever. But it was just, okay, I have the gene. And how do you feel and all the rest of it. Well, I feel fine and stuff like that. It was just like, okay, let's just ... But that's me, I think, in ...*
> *Ms. X: Day to day life.*
> *Ms. W: Like, okay, let's get on with it. I don't want to sit here and discuss it for hours. And I guess other people do.*
> *Ms. X: That was part of it, too. I was the same way. I didn't want to sit around and discuss it. But, I mean that's the way that we are. I'm sure there are people out there who want to sit there for hours and talk about it, right?*
> *Ms. W: Yep. And it's knowing that you have the resource. I mean, we can always call [the genetic counsellor]. We can always call [the nurse], or I mean, my oncologist. They're always there for you.*
> *Ms .X: I think we're more realistic. There isn't any point kicking and screaming over something that we don't have control over. We do to a point and I think we've all done what we can. And what's the point in going crazy beyond that. That's just going to bring it on.*
>
> *Ms. N (positive): Well, I found out, I didn't go down with anybody when I found out that I had the recessive gene. I was just there on an appointment by myself. And it still, it's always a shock to your system. I'm a physical person and I really appreciated [the genetic counsellor's] ability to get up*

> *and just hug me. I mean, she wouldn't have, I think if she thought I wasn't, I wasn't needing it or, whatever.*
> *But, just her, you know, willingness to, yeah, her perception of what we all needed. Like when we all went together, she knew that we all had each other and she was fairly professional, even though she sat really close to us and gave us a lot of eye contact and everything. Still, when I went by myself and she talked to me and she was like almost knee touching knee, sort of thing, and she just leaned right over and hugged me.*
> *And, I asked her a lot of questions, too.*

### ***Reservations about Counselling***

Certain reservations about genetic counselling, or suggestions for improvements, were raised during the course of the interviews. The most serious of these had to do with the availability of genetic counselling and testing services and the criteria used to determine who was eligible to be tested. The first of these issues, for those who had gone through the counselling process most recently, was the long waiting list to get in to have an appointment with the counsellor. This was particularly disappointing for those who waited a long time, only to find out they were not eligible to be tested.

> *Ms. R (ineligible): I don't know, I think a year wait is a long wait to get into genetics, for what I had learned ... I could have gotten a letter explaining the whole situation a lot sooner.*

Several women who did not meet test criteria felt very frustrated with this experience, particularly since someone else in their family would have to develop breast or ovarian cancer in order to meet testing criteria. While several said they could not blame the genetic counsellor for this, since it was not her decision to make, others saw the genetic counsellor as a type of gatekeeper, since that was the person who had told them that they could not have testing.

> *Ms. G (ineligible): Actually, there was a bittersweet sort of thing to it, because I wanted to find out.*

> *Ms. E (ineligible) Like we wanted to be able to go in there and be able to have some tests done. I mean obviously, [the genetic counsellor] said that she's actually had people walk out screaming mad at her, because they can't do those tests. And we're fine with that because . . . Well, we think that they could probably take some blood tests and compare our blood to other people's blood rather than somebody in our family. But, if it's all for genetics, then I guess that's all past the point, that's not exactly what they're looking for. But we kind of want to see how it compares, not necessarily just for our family, but to other people as well, since we don't have, we don't want to wait for somebody to be sick in our family to have to do that.*

Aside from the issue of needing a relative with cancer to start testing with, some questioned the counsellor's evaluation of their risk without testing, which is based on epidemiological tables. The issue of criteria for high risk status was particularly contentious if a woman felt it was unclear whether the counsellor understood her objections to the risk criteria, a miscommunication causing frustration. While one woman simply felt the counsellor's numbers could not be relied upon without a test and went ahead with her previous plans to have a hysterectomy, another woman felt very frustrated that her general lack of female family members made it hard to determine her level of risk. She felt that the general statistics did not fit her case very well.

> *Ms. Q (ineligible): It was really frustrating. Because she kept saying, if there were eight people, whatever something, you know, you'd be at eighty percent. And I kept saying, [counsellor's name], that, you can't, that doesn't work for me. Like you cannot keep telling me I'm low risk when there's only one person in the sample. It's an unknown. So, yeah, it was frustrating. So, what do they do with people like me? ... It's been kind of pooh-poohed, no, no, no; you're over reacting. But, then it goes back to given that there's only one person. And then I go back to my, there is only one person and she's dead, you know. So, I guess, we all have trouble with my case, hey?*

For those who could have testing, some found the wait for the results hard. Some had trouble with the waiting period before the test results were available. Others were impatient of the wait involved in scheduling a meeting with the genetic counsellor to find out the outcome of the test. Waiting a week when they knew the results were available was difficult.

One woman felt that life insurance and other issues that could be detrimental to a person's future after testing should be discussed in more detail, either by the genetic counsellor or in a group setting, since these issues had so much future importance.

> *Ms. F (negative): So, you almost need to, in a way, have group sessions, I would think, [it] would help. You know, if someone is thinking of genetic counselling it would be great to have, say a conference of some kind, a workshop available to people, where you have someone from the insurance industry and what have you, that deals with all those issues right up. Like a classroom situation, and say 'this is what's going to happen', I mean, they're having it for condo owners right now, you know. The pitfalls of becoming a condo owner, okay, you really need that kind of session, I think, for genetic counselling. And it would also be good in a greater setting of more than just you and a counsellor, because then there's going to be questions coming from everyone around you. If nothing else, there'd be a good discussion on the general aspect of it, without dealing with your specific case.*

While some of the genetic counselling clients received a follow up letter, as did their physician, for others, only their physician received a letter from the genetic counsellor. For the two women who mentioned this, the lack of a letter was felt to be a loss:

> *Ms. R (ineligible): It would have been nice to have something on paper, you know, come to me so I could have kept it. Sometimes it's easier to figure things out on paper than it is to just hear someone talk. You can put all the facts together. You know, for a lot of people that do go there, or, whether they [go] to the lab or to the doctor, it's sort of like a white coat syndrome. It sort of goes [in] one ear and out the other, and it doesn't really help them all that much. 'Yes, yes, I understand, yes, yes'. But it still could mean not really understanding anything. So, even some sort of follow up letter, of some sort would be good to go to a patient.*

### *Genetic Counselling: A Summation*

Genetic counselling for hereditary cancer susceptibility involves a lengthy protocol designed to make sure that people who decide participate in genetic testing understand all the benefits and risks involved. Although some were impatient with the counselling process at the time, in retrospect, this aspect of the counselling session was considered important. Ms. Z's comments illustrate what the process felt like to go through and how things that didn't seem important at the time became so later.

> *Ms. Z (positive): We discussed all the details of what's involved and the outcome and, you know, here's what we might find out, here's what exactly it is that we're looking for and here's, what it could mean to you. I believe they went over the risks and all that sort of thing and they were very good. And then they said, now, wait four weeks and if you're still ready to go forward with this blood test, we'll get together again.*
> *So, they gave you some time to think about it.*
> *At that point, I thought it was way too much time. Because I was, you know, I'm ready, you know? There was a lot to think about. They gave you all the scenarios to think about, about insurability and all that sort of stuff. But, to me, it wasn't ... I mean, we were under a life insurance policy, it was a five year policy. But I figured, well, you know, I'd much rather have this information and take the risk of potentially not being able to be insured. You know, I want to know, I don't care. I want to find out right now.*
> *So, you don't realize how important it is to know that they're there and if you want to give them a call or you want to change your mind or if you have another question, or whatever. And the follow up as well. Of course, I didn't think I would need it, at the time. So, you're kind of not really listening. But, I guess, subconsciously, to know that there's going to be somebody still there, after all this, regardless of what the results are is kind of good to know. So, that was important to me.*
> *And they did say we really want to make sure that this is what you want. And they did tell me that's why we're waiting the four weeks and that's why we're talking to you again. And you have every right to change you mind at any moment.*
> *But you're not listening. I mean, for me, I wasn't really listening to all of it. I just wanted to know, you know?*
> *But looking back now I understand why they took the time. It's important that you have that time.*
> *Even though at the time, I didn't think so, looking back on it now, I can appreciate [it] and I can appreciate why they went over everything again, because there are parts that you don't hear, you don't listen to, or you*

*forget. And it's very good that they've gone over things several times and explained it to you and asked you, do you have any questions.*

*And then when they did give you the information [test results], they gave you time to sort of sit and think and cry or be happy or whatever, depending on the results. And then again, they re-explained everything.*

*Because at that point, you're going, okay, I didn't listen to you the last three times, because I didn't think that I was going to have it. And now you're telling me I do, can you explain it all to me again?*

*And they did and they were more than happy to, so. And then they started to explain in more detail about what the follow up would involve. It hadn't been set up at that point, but they were working on getting the follow up clinic running. And that again, was, you know, a big security blanket. It's not like they've told you something and then they said, oh thanks for your participation, good bye. You know? Okay, see you later. It wasn't at all like that.*

*It was very nice knowing that we're going to keep going with this and we're going to see you through. So, that's a good thing to know.*

*Yeah, I think it's a good thing [genetic testing]. Under a controlled condition, though. I think it's important that it's done the way they did it, with the taking the time to explain what it is they're doing, what it is they're looking for, what it is they're identifying, how it'll affect you. What difference it might make in your life and here's what we can do. We can't change it, we can't stop it, we can't prevent it, but here's what we can do to monitor it and help you through the next twenty years, or whatever, right?*

*Like I say, I think I agree with all this genetic testing. I think it's a wonderful thing. But I do believe there has to be follow up, and a lot of consultation before and a lot of follow up after, especially if your results are positive.*

## Genetic Testing

There is considerable controversy surrounding genetic testing in general (Jallinoja et al. 1998). Some of the academic and popular critiques of genetic susceptibility testing for diseases like breast cancer are that testing could lead to employment or insurance discrimination and that the results could cause emotional distress without providing a real health advantage by being able to prevent cancer (Nelkin and Lindee 1995) (Mitchell 1999) (Elwood 1999).

Discussions in the interviews suggest that while those actually being tested (or who are interested in being tested) do recognize many associated disadvantages with being tested, most see these as minimal compared to the benefits of testing. These benefits include a sense of control over their own health, access to medical support for screening, closure of worries about family history, and benefits to society as a whole. Disadvantages that were discussed include emotional distress, discrimination, and increased difficulty making choices about whether to have children.

### *Benefits*

#### Control over Health

Many saw the test as helping them to make better decisions about surgery and screening, thus affording them a chance to control their own health. It gave them the ability to decide whether or not to have surgery based on firmer objective grounds and opened up wider avenues of choice. Some argued that they had the opportunity to become more strict with themselves when it came to screening regularly (including breast self exam) or having healthier lifestyles (quitting smoking, exercising more regularly, or eating healthier foods) if they had positive test results.

> *Ms. H (positive) "Emotionally, you offer people the ability to control their own health. To me, that's the biggest thing. My decisions are based on what I want. I'm not forced into... I looked around and, you know, it was good to see, we saw a lot of people with cancer, and all of them were reacting and it was nice not to have to react.*
> *You had time to think and decide what you wanted to do and then...*
> *The decision was mine.*
> *And then, I have a cousin who actually had prophylactic mastectomies years ago, because she's the one whose five sisters had breast cancer and it turns out she didn't have the gene. Now, she's fine with that, but at the same time, it gives me the opportunity to make a decision based on sound, medical data. So, I can know, I have the gene.*
> *This is what I look at on one side, this is what I look on the other side and then I made the decision.*
> *It's my decision.*
> *And I have to live with this.*

> *Ms. U (negative): You can do something about it if you find out you have it, yes. And if you just leave it and not know, then, you're probably not going to do anything until they actually tell you you have it. And then it might be too late.*
> *Like my mother, I think if she had known beforehand and had her, like she had a hysterectomy years ago, but they didn't take the ovaries out. And that's where she got, she got ovarian cancer. Well, if she had known about this gene testing and got tested, she would have gone and got her ovaries out and she probably would have been still alive today, I think.*
> *She was a little bit too early, that's all.*

> *Ms. T (negative): Well, the benefits, you can change lifestyle, you can do preventative things. You know, if you're eating wrong or doing the wrong thing, you can stop doing that. You can make changes in your lifestyle. Maybe you're going to, maybe you're putting things off and maybe you shouldn't be putting things off.*

> *Ms. Z (positive): But, the advantages are, the good side of it is that, I'm aware now that I'm in a higher risk group than most women, which I consider to be a good bit of information to have. It doesn't make me feel bad that I know that. It just makes me feel lucky that I know that.*
> *I know had I not had the testing done, I probably still would be at the stage where, oh yeah, I guess I should be doing that, I should be checking myself every month, but I probably wouldn't be. Right?*
> *It's just an awareness that I'm glad to have.*

## Access to Medical Support

Medical support is an essential part of a woman's control over her own health, since it provides her with options: screening, surgery, or just access to a professional medical opinion about her worries. The labelling of 'high' or 'strong' risk that can follow genetic testing can provide access to this support, or, if the results come back negative, it can negate the need for increased support.

> *Ms. P (positive): I think there's a lot of benefits.*
> *Just the very fact that we can go and be with doctors who are so knowledgeable in this area. And I know that my regular GP, she doesn't test as thoroughly and she's not as knowledgeable, obviously, and she hasn't studied this area. So, just to have contact with these people and have them, sort of monitor us, I think that's such a huge benefit.*
> *And I think that, the biggest benefit is, if we do develop cancer, that it will likely be found out well within, while it's still in the beginning stages.*
> *Because we are seen every six months.*
> *So, I think, obviously, our life will be extended, our chances for survival will be much, much greater.*
> *And to me, that's a huge benefit, obviously.*

> *Ms. Y (positive): Which again, I know for a lot of people, I know even when we decided that we were just going to have the testing done, there were certain people in our family we didn't tell, because we knew the response, the kind of people that they are. Like, are you nuts? Why the hell would you want to know that?*
> *We were like, well, think about it. Being how young I am, if I walked into my doctor's office and said, look, I kind of have a family history of it, I want a mammogram, they'd say no.*
> *So, I feel like I'm really lucky because I have that opportunity for a lot of screening. Where as most people my age and older aren't allowed to have that.*

> *Ms. X (positive): Even for me, in not having anything cancerous, other than the gene, I'm better off than 90% of the women out there.*
> *I have better chances at catching early detection.*
> *Which is comforting.*

Closure of Worries

Another benefit perceived as outweighing the disadvantages of testing was that it could bring about a sense of closure. Giving the women a better idea of their risk of breast or ovarian cancer could eliminate nagging worries about family history. The possible anxiety associated with being told one has a higher risk of cancer is balanced by the anxiety that a woman often already feels over the issue. Several women mentioned how such anxiety was unavoidable given family history. Testing either relieves the original anxiety by showing one has a lower risk or, for those who test positive, it indicates the best avenues of care for these women, so that they know that everything has been done that can be done. One woman expands on this theme, pointing out that positive results are tough in the short term, but also carry long term benefits.

> *Ms. F (negative): So, it's right through, and because they were all so young and I was so close to them ... I mean, there were two of them, three of them with cancer in the 1960's. So, there's just no way you can avoid it. I mean we were such a close family. And you're living with this disease constantly. And you just know that there has to be something within the family.*
> *So, that's, you know, I've known about cancer since I was young. And, of course, there's always the fear that you're going to be one of them.*
>
> *Ms. T (negative): I don't know, the disadvantage ... Because I don't think, if you found out you had it, I don't think you'd worry any more, because you'd already worried, the whole time, because if you're, you know if you have a family history, that's always there. It's really funny, you know, because that shadow's always there and not always for me, but you don't realize it after until you talk to people. My husband thought I would automatically get it, my brother-in-law and sister-in-law thought, you know, because it's the whole family.*
>
> *[Ms. X & Ms. W, both positive, daughter and mother]*
> *R: So, were there any other benefits that you saw, that?*
> *Ms. X: Peace of mind.*
> *Ms. W: You don't worry about it, do you?*
> *Ms. X: Now?*
> *I don't even think about it.*
> *I know my place in it right now and I know it's not something...*

> *Even if there was something to be worried about, I've done everything I can, everyone has, so, whatever happens, happens.*
>
> *Ms. H (positive): So, it really could cloud your judgement a lot. Especially, you know, in the midst of it being new.*
> *After you've had it for a couple years and you're living with it and you can see whether or not it's going to have any great effect on your life, then you can make some decisions. But the good thing, too, though, is that my daughter will have the latest in screening, you know, and also the latest in genetic therapy. And I'm hoping by the time she's old enough, and my boys, as well, are old enough to have to worry about this, that there will be some sort of gene therapy that will resolve it for them. And there's a good chance that will happen in their lifetime, I think.*
>
> *I think, in the short term, it could be looked at as a bad thing, better off not knowing. But in the long term, I think that, at least from the perspective of somebody who has this, you know, we need to get some perspective back on it in the, you know, the general scheme of things, it's not as bad as some people have it.*
> *You're armed, I think you're better armed.*

### Societal Benefits

Some saw the testing as providing a societal benefit, by identifying those at high risk of the disease and then allowing for the possibility of prevention of the disease through prophylactic mastectomy, or gene therapy. This was seen to lower the burden of the disease on society as a whole and cut medical costs needed to fight cancer.

> *Ms. H: From my perspective, I think, monetarily I think it's a cost saving. Because I think that you can isolate a group of people that are very, very high risk for cancer and you can offer them prophylactic treatment, that in the long term saves money to health care. I don't have any doubt about that.*

Tied in with the societal benefits is the hope that the knowledge gained from genetic testing will be part of wider research, which will be able to prevent cancer from developing in the future, particularly the future of the women's own children.

> *[Ms. O & Mr. X, both positive, daughter and father]*
> *Ms. O: And also another benefit is maybe, they'll learn enough through this gene, by the time our kids are around our age, when they'll be more susceptible to the cancers, that they'll be more answers.*
> *Mr. X: Maybe a cure by that time.*
> *Ms. O: Yeah.*

### ***Disadvantages***

#### Emotional Distress if Positive

Emotional distress after receiving a positive test result for a genetic cancer susceptibility was recognized by all. This distress was placed into the wider context of improving their chances against cancer and facing preexisting worries about family history. Thus, while it was definitely emotionally overwhelming at first, this passed with time and was later associated with larger benefits.

> *[Ms. X & Ms. W, both positive, daughter and mother]*
> *Ms. X: I think there are numerous benefits.*
> *As for drawbacks, it's just the emotional, I think. And I mean, I haven't even gone through every thing I've seen everyone else go through.*
> *Just the emotion.*
> *It's hard.*
> *It's life changing.*
> *And we all went through our emotions. I mean there were times when mom was strong and we were bawling and then there were times when she was bawling and we were strong. So, that's what I mean by seeing my mom and my aunts go through it, it doesn't make me as scared of it. Because it wasn't such a hush, hush, horrible tragedy incident.*
> *Ms. W: Yeah, when my mother, cancer was just a death sentence and you didn't talk about it. And, I mean, my mother didn't talk about it. I mean, that must have killed her. I mean, when I found out [that I'd received positive test results], I mean, I took my kids out to supper and we talked and we discussed it and we had drinks and, you know?*
> *Ms. X: We got blitzed and we cried and...*
> *Ms. W: It's just like, this is the way it is and I just think that it's really important to be open and honest about it. I just feel sorry for people who don't have anybody.*

> *[Ms. O & Ms. N, both positive, sisters]*

> *Ms. O: And I think back of when we first started this and I think of how our reactions were, my reactions of...*
> *As time goes on, because, at first it's surprise, it's the shock, it's really overwhelming. I found it very overwhelming when I found out. And I was a little upset. I wasn't really rational about how I thought about things. As time has gone on, I find that I, the way I look at it is a little bit different from a year ago, what I felt about it.*
> *Yeah, it's really, you know, the information, as you feed on more information, the more you see your doctors and everything, the more secure you feel in it. You realize it's a real blessing rather than...*
> *Ms. N: Knowledge is power and I just felt that that's what it's been for us.*

> *Ms. T (negative): I had gone to, just after my testing, I went to a breast cancer lunch, and there was a surgeon there. And I was so angry at him, I almost wanted to go and punch him one. He spoke in front of all these women and said, he didn't see the sense in genetic testing, because it would just make people worry.*
> *I just think, what is it he thinks these women have been doing their whole lives, you know?*
> *They've been worried their whole life.*
> *And this was before I found out that I didn't have the gene.*
> *But I was so...*
> *I thought, you have no idea what you're talking about.*
> *And it wasn't a, I've been to some breast cancer things were it's been a forum, you know, where you could talk back. And that wasn't really available at this time, so I was like [expression of frustration/anger].*
> *R: So, if you had been talking to him you would have just said that?*
> *Ms. T: Oh, yes!*
> *I said you're crazy, I would have told him.*
> *You worry the whole time; you worry your whole life about it, because that's there. I mean, you're not cleaning drawers all the time because you think you're going to die. But, it's back there.*

## Discrimination: Life insurance, employment, and social interaction

Potential loss of life insurance was mentioned by some. Either if it had happened to that individual or someone they knew, or they remembered the genetic counsellor mentioning it. It was usually mentioned as more of an inconvenience, rather than as a major drawback. However, there was a general concern that the confidentiality of test results needed to be carefully guarded. Only one person mentioned the possibility of employment discrimination. Another mentioned the difficulty with deciding who to tell and some of the social ramifications of having the information generally known

> *Ms. H (positive): Well, the drawbacks, I think, are, you know, what is society going to do with this information?*
> *I have already been, the company that insures our mortgage wouldn't insure my mortgage this last time. Now, whether or not they had the wrong information, I don't know. I filled out a questionnaire, but I don't know what I put on it. It would have been a family history, if nothing else.*
> *So, I think that, I think that the information has to be carefully guarded and also that the long term issues need to be looked at.*
>
> *Ms. F (negative): Also, I have two children, one of whom is a daughter. But at that time [when I was involved in testing], I would not allow them to take the genetic testing. I thought, if I have it, then fine. But, if not, I would prefer that they don't because it's going to affect them, in terms of employment, insurance and everything else.*
> *She [her daughter] is only twenty-four at the present time. She's got, hopefully, a long life ahead of her, hopefully, a healthy one, but I just don't want that kind of employment and insurance discrimination that she could face with that. And it could also affect my son as well. I mean, you know, a genetic thing in the family, I'm sure it's going to have some kind of affect on him as well, in terms of employment, or what have you, whatever kinds of discrimination is going to come out of this. Because I'm sure, right now it's probably hidden, but I'm sure it's going to take place more and more.*
> *R: So do you think it could actually be harmful, then?*
> *Ms. F: Oh, yes. I think it could, yeah. You almost need someone from the insurance industry to document, you know, this is what can happen ... You know, that would really be helpful.*
> *And you have to deal with the confidentiality, because if you apply for insurance policy, one of the questions is going to be, have you ever had genetic counselling. If you lie to that it voids the policy and if you're truthful ... And, I think you're giving them the authorization to ask for those records.*
> *So, to me, that's very important.*
>
> *Ms. T (negative): But, [the genetic counsellor] just mentioned insurance. I had never thought of that before.*
> *And she mentioned people might feel different towards you, but I tell everybody, I'm very open and I didn't find that, I just found support, so. I think it's the type of person you are.*
> *R: And you think [the benefit] outweighs anything like the life insurance that [the genetic counsellor] mentioned?*

> *Ms. T: Oh yeah. Well, especially, I mean, if you could find out, like a, peeking through a window into the future and you think well, that is that risk, well then okay...*
>
> *[Ms. W & Ms. X, both positive, mother and daughter]*
> *Ms. W: Because one of the things they tell you in the counselling is be careful who you tell. You don't think about that. But, I told one person at work that I thought was confidential and then it kind of went around and it was just...*
> *People looked at you differently and it...*
> *You know, I mean, we got an email today and one of the girls at work, she was 38 years old, she was healthy, she was everything and she had breast cancer.*
> *She died over the weekend.*
> *You know, 38 years old.*
> *And like, people would come up to me and it was just that look on their face.*
> *And it's like, I didn't really know her, you know, or, you know, it's just like, because they think...*
> *Ms. X: You're one and the same species.*
> *Ms. W: Yeah, right.*

### Reproductive choices

Most of the women interviewed already had children, or had chosen not to have children. However, it was mentioned that for the next generation, being shown to carry a genetic mutation could make decisions about whether or not to have children more difficult. The issue is complex. There is a reluctance to suggest that the genetic mutation is a reason for not having children. However, there is also a recognition that the information is difficult to disregard. The following comments by Ms. H and the discussion on this subject between Ms. N, Ms. O, and Mr. X (two sisters and their father) illustrate some of the tensions between trying to act responsibly, without overreacting, when it comes to decisions about children:

> *Ms. H (positive): But I think it needs to be looked at really carefully and the information needs to be reviewed very carefully, so that in the sense of, if somebody has the gene...*

*I mean, I've had my kids, but if you found out you had the gene when you were 22, is that going to make a difference in terms of whether or not you have children? Now, I found out I had the gene when I was seven months pregnant, you know, and they were looking for it before I got pregnant and I remember thinking, maybe I should wait, before I think about having a third child. And then somebody said to me, you can't, sort of, put your life on hold while you're waiting for...*
*So, I went ahead and there were times when I thought, oh, maybe I shouldn't have bothered, because I have a girl now and it's different for girls than boys, I think. It's more immediate, the ramifications are more immediate for girls than boys.*
*But, I can't imagine, because of this, not having her.*
*So, it really could cloud your judgement a lot.*
*Especially, you know, in the midst of it being new.*
*After you've had it for a couple years and you're living with it and you can see whether or not it's going to have any great effect on your life, then you can make some decisions. But it would be really tough if you were younger and trying to decide if you wanted a family or not to think about having mastectomies because that would mean you can't breast feed, or hysterectomies, I mean, it would make a difference.*

*[Ms. O, Ms. N, & Mr. X, all positive, two sisters and their father]*
*Ms. O: You know, that's something that I've discussed with my three girls, in their own time, if they want, they can have the blood test and go through the study also if they so choose. And I do hope that they would do that down the road, because if they are a gene carrier, then they'd become, they'd go through the same testing...*
*Ms. N: Become knowledgeable. And also they're more knowledgeable about what's happening. And I think it also gives them an opportunity to make some important decisions ahead of time, decisions that we never had a chance to make, because we didn't know, none of us knew that we were carriers.*
*And, I've had some people say, well, would that have changed, would you not have had children? And I can't even contemplate that, because after you've had your children, I mean, you can't contemplate not having them. But, for them, it gives them a chance to talk to their spouses or their wives or their husbands to be and make those choices. I think, even, whether or not they'd want to have children.*
*Ms. O: Yeah. The only drawbacks that I can see in this at all, is how it affects our younger generations and what kind of decisions that it, it may be very weighty for them when they're starting to think of family and things like that. Because, you know, when we started our families, it was nothing but blissful, oh, you know, looking forward to a new baby. It was the most exciting thing in the world to share that with your loved, most beloved, you know, your husband. And that's something that, I wonder how it's going to affect our kids in the future.*

> *I hope that, for them, that they can look forward to having children and that, my hope would be that they would go ahead and have kids. That everybody out there has a certain amount of chance at getting sick and dying, right?*
> *But I think that's the biggest scary thing for me, is thinking that it may affect them in the sense that...*
> *Mr. X: If they get into a program like this, it minimizes the chances, the worry of maybe having terminal cancer. Maybe you might get cancer, but it's not terminal.*
> *Ms. O: Exactly. There's a lot of ... I think the positives way, way out weigh any negatives. And that's the only negative I can think of.*
> *Ms. N: But, I guess it's just the fact that our children now have something to discuss with their spouse and it's still a decision that has to be made.*
> *Ms. O: Most definitely.*
> *Ms. N: But starting with our children, if they do have the gene, they're the first knowledgeable generation of it. We, it didn't start with us, it starts with them. And so, by them having children, they know that they could pass it on.*
> *Ms. O: It's a whole different way of looking at things than it is for us.*
> *Ms. N: Because it's more of a decision to be made on their part.*
> *Ms. O: Yeah, yeah. But at the same time I look at it and say, oh, I wouldn't want it to stop them either. But at the same time you hear that and you go, yeah.*
> *Mr. X: Well, life goes on. Diabetes has been around, I don't know, it was around when I was a kid and they knew that it was passed on in families. At that time, at least, they were sure of it. And that didn't stop people from getting married and having kids.*
> *Ms. N: But, I don't know daddy, I feel, people are a little bit more knowledgeable about this, and doctors are not the gods that they used to be. Doctors have come down to being people, too. And, yeah, I think we're getting to the point when we're more involved with our health and wanting to take the precautions, knowing what kind of things ...*
> *Wanting to stop it, so that we don't have to be going to a doctor all the time. Even properly taking care of our bodies, not putting ourselves at risk in jobs that you're taking in asbestos or whatever. I mean there's all sorts of things that have happened over the last, maybe even five, ten years, that have given us such a wide knowledge of what causes a lot of different things that we're not going to a doctor as a cure all, you know? We're not going to him and saying, play god and make us well.*
> *We're now, I think, more...*
> *Ms. O: Training ourselves to help prevent these things from happening.*

Those who were young, and had not yet had children, did not discuss a BRCA1 mutation as a reason not to have children. They tended, instead, to lead the discussion into how quickly science was learning about gene therapy or cancer treatment and hoped other measures would be discovered before they had to worry about their children. In addition, the genetic inheritance of a susceptibility to a disease, which may appear later in life, brings up questions of life quality, as well as life quantity.

> *[Ms. W & Ms. X, both positive, mother and daughter]*
> *Ms. W: By the time you have kids, maybe, they'll be able to...*
> *Ms. X: Alter it.*
> *Ms. W: Or take it out, or, with all the stuff they're doing now.*
> *R: Do you think it makes any difference?*
> *Ms. X: How?*
> *R: To future plans, in terms of kids, or not, knowing?*
> *Ms. X: No, I mean, no.*
> *I'm not at that step yet, where I...*
> *But it hasn't changed me wanting kids. It wouldn't stop...*
> *I mean, it's just like you saying, if I were to say that it changed my wanting to have kids, it's basically like, oh, I wish my mom hadn't had kids. Why did my mom have kids, then?*
> *Now it doesn't, my life's fine.*
> *I'm happy.*
> *I have a long life ahead of me, right?*

### *Views of Those Ineligible for Testing*

Several of the ineligible women were not particularly concerned about being unable to have testing. One woman said she was less interested in testing, since she did not have children. Another said that she might be worried all the time if she were shown to test positive. This did not constitute a rejection of testing and the biomedical knowledge associated with it. They appreciated the counsellor's knowledge and her discussion of their risk tables. However, their inability to have testing did not bother them.

> *Ms. K (ineligible): In my case, I can't get the genetics, so.*
> *It would be interesting to, for you to find someone who can get the genetic testing done, the DNA test done, and then find out, okay, they do have the gene. Wow, how does that change your life? I don't know how I'd, maybe*

> *just the fact of not knowing, I'm feeling, oh well, there's nothing I can do. I don't know. But if I knew that I had it in my genes, I mean I would be more nervous on a daily basis.*

The lack of testing was regretted by another woman, since she would have used the information to decide on whether or not to have a prophylactic mastectomy. However, she also put this in perspective, with her newly found knowledge of how rare hereditary cancer actually was.

> *Ms. G (ineligible): Actually, there was a bittersweet sort of thing to it, because I wanted to find out. I thought maybe I'd be able to find out with my own tissues or whatever, or my own blood, whether I was genetically predisposed to it, highly. And if that was the case, then I was going to go on to surgery.*
> *On the other hand, I found out a lot of information that made me feel more assured. You know, the fact that only 20% is, you know, genetic and so, I felt a little better. But hey, maybe I'm going to be the one that doesn't get it in our family.*

For others, the inability to get the results from the test was very disappointing. They were still concerned about their hereditary risk and would have wanted the test in order to negate this worry, or to be officially recognized as having a strong risk, in order to validate increased medical support. This seemed more difficult for those who were young, or those who were concerned about the history of ovarian cancer in their families and were skeptical about the efficacy of ovarian cancer screening catching the disease early enough to prevent mortality. One woman commented that her plan, before genetic counselling was to have her ovaries removed. Genetic testing would have just been a reinforcement of that.

> *Ms. D (ineligible): But it's been difficult for us because of our ages, because people don't take you seriously unless you're in, you know, your late 30's. And so, they're taking our aunts quite seriously, but they tell us "oh, you don't need to have this until . . ." you know you're 27 or 30 or whatever, but in my opinion that's a load of hooey, because my mom died so young.*

*And so, we were really interested in the medical genetics testing and everything, but we were rather disappointed that nothing can be done because we don't have a living relative with cancer.*
*We don't want to wait for somebody to be sick in our family to have to do that.*
*I guess for [my sister] and I, our decision, I mean both of us have talked about, because mom was so young, if perhaps we did have one of these genes, whether or not we would consider getting, after we finish having our families, getting a full mastectomy and breast reconstruction.*
*But we also didn't know that it was so closely linked to ovarian cancer, so, now that sort of tossed another point into this. But both of us would seriously consider that as an option because of the way, because of the way our mom's death has affected our lives.*

*R: So, how do you feel about not being eligible to be tested?*
*Ms. Q (ineligible): Well, the way she explained it, it's not even possible, technologically possible right now. So, like I feel really ambivalent about what I should be doing.*
*You know, I wonder if I'm doing enough.*
*I mean, it's like, starting the screening program, I've been doing breast self exams, annual mammograms, when I was just at the Cancer Agency, they did the ovarian screening.*
*But, you know, I wonder if that's enough.*
*You know, because I might be one of those, if there were seven, you know those families? Like I have no idea of knowing.*
*R: So, it's just the uncertainty, then, that?*
*Ms. Q: Yeah, and I wonder if I'm doing enough, if I should be doing something else, you know. Like, in those kind of families, women have radical mastectomies, right?*
*That was when I first went to [the genetic counsellor] and said, should I, should I just get them cut off? No, no, no, she says, no, no, no, there's things we can do before that.*
*But, you know I just felt, I do not want to die from breast cancer at a young age,*
*I just do not.*
*So, I'm kind of trusting what they say at the Cancer Agency and wondering if I'm being foolish. Like, wondering if I'm taking enough responsibility, right? I just hear horror stories about undetected cancer, you know? And then I think, I've got this whole team, like I've got somebody now, they're just all looking for cancer in me, right?*
*I'm kind of like, oh, I guess I'm really low risk, you know, and maybe I am. But see, then again, I've studied statistics and it would be different if we had five people in the sample and only one developed cancer. It's just a complete unknown. It's been kind of pooh-poohed, no, no, no; you're over reacting. But, then it goes back to given that there's only one person. And then I go back to my, there is only one person and she's dead, you know.*

> *Ms. R (ineligible): Well, what happened is, I talked to my doctor, my GP, and she was concerned that I was so adamant about having the ovaries out, and all that sort of thing. So, she contacted the genetics clinic and talked to a doctor there and said that they could probably trace my background to my mother and my aunt.*
> *And so, we booked an appointment, which was about a year, or something. We had a long time before we could get in there. And then when I got there, they basically told me that I couldn't do that, because relatives were already deceased and...*
> *But basically, it was quite disappointing. Because then I thought, my kids could have been screened, or ... And my sister has a daughter, as well.*
> *... And I realize that there's more chance of getting breast cancer, because of being on the estrogen [hormone replacement after the hysterectomy] and all that. But, I think it's easier to find breast cancer than it is on the ovaries. And they really couldn't give me any percentages. Which is why I basically went ahead and did a [hysterectomy - not said].*

### ***Dissenting Voices***

It is worth noting that not everyone is in favor of testing. Not only were those who refused testing omitted from this study, but also, some people mentioned relatives or friends who were not interested in testing. Some were supposedly just not interested, while others were said to be afraid of discovering they were positive. These individuals were often mentioned in the context of being slightly irresponsible about their health, or causing themselves needless worry by not finding out if they were, in fact, at higher risk.

### ***Advice***

All women were asked what advice they would give to others in their position. The topics present in their answers give a snapshot of their views on genetic testing and motivations for being involved. Many commented again on how knowledge was a “good thing” and this would help one to take control and avoid worry. A few people also commented that balance and perspective were important in using this knowledge and not overreacting to it. One woman, in fact, commented on the need to be aware of sporadically occurring cancers as well as hereditary ones in order to have a more accurate overall view. Several people also mentioned that it was important to be proactive about better health, be that screening, preventive surgery, or adjusting your lifestyle to be healthier.

> *Ms. J (ineligible): Uhhhm, yeah, I think the main advice is get all the information that you can and, because I found since [my sister] passed away, the more information I have, the less scared I was and I don't think it's good to be scared about it. Because, I think that's not good for your body anyways. Yeah, I think that would be my main advice.*
>
> *Ms. O (positive): I'd say, go for it.*
> *Knowledge is ten times better than ignorance. I mean it's a thousand times better.*
> *If there's a chance that it's there, definitely do it. Take that little blood test. It's definitely better to find out and have the knowledge. And feel good about, at least, trying to do something about it that can maybe help you or your generation.*
> *It's much better than just putting your head in the sand and going well, I don't want to hear about it and I don't want to know anything about it.*
>
> *Ms. H (positive): I guess, it would be don't rush and become informed. And after awhile, I mean, we had to take breaks, both my sister and I said, okay, we've had enough, we're overloaded here, we don't want to hear any more about cancer. We don't want to worry about it. Because it does overwhelm you after a while to constantly be thinking about cancer.*
> *[But] then take control and make your own decision.*
>
> *Ms. A (ineligible): I think, I think it's very important not to be preoccupied with one potential affliction over any others in the world. Between natural death, natural disasters, accidents, honestly, I don't think that we should be focussing on any one thing if we don't have any reason to. I think we should just generally do our best to look after ourselves and have a good outlook.*
>
> *R: Would you have any advice for a woman in a similar situation?*
> *Ms. G (ineligible): As mine, you mean?*
> *Do self exams and mammograms.*
> *And I can't believe how many of my friends, as I say, do not do either one. It blows my mind. And then when I tell them, 'hey, 80% of the population is*

> *getting breast cancer without any hereditary', then they perk up, but they still aren't doing it, you know? It's amazing to me.*
> *So, I think, yeah, that is something that I think needs to be done, the population needs now to learn that it isn't just if you have someone in your family, they've scared everyone over on this side, like me, so much, with the news that yes, we found a genetic link. So everyone thinks that that's the only way you get it now. So they're becoming lazy about getting mammograms done, the general population. Because they think, oh, well, I have nobody in my family.*
>
> *Ms. K (ineligible): If you're in a family that's, so-called, high-risk, I would say, you know, just have a good look at your lifestyle and make sure you do all you can do to help yourself now. You know, it's like some woman who is letting herself go a little bit, eating all kinds of bad food and not exercising and having a history of all that, I say, well, gee, you know, how can you talk much? And the more you take control, the less, I think, you develop a fear of developing cancer.*
> *And that's bad, you know.*
> *Your life is tainted with that, you know, in the back of your mind.*
> *That's not a good way to live.*

Another point of interest was the need to have enough support while going through this process of discovery about family risk, or just for life in general. While some saw this as being best provided by counselling, or a formal support group, others mentioned the importance of family support.

> *R: Would you have any advice for a person in a similar situation, to yourself?*
> *Ms. F (ineligible): Oh, God. Would that person listen to it? I know I wouldn't have listened to advice from anyone else on it.*
> *Good luck?*
> *It's such an emotionally charged decision and sort of, at least it was for me because of everyone else in the family. It's sort of like a blister that never sort of heals, never goes away, you touch it, 'ouch', but normally you don't go anywhere near it. I don't know.*
> *But it is important, I think, to have an objective avenue, because there's so much of the emotional that comes with this, so much emotional baggage, which comes with these fears, and you need the objective point of view.*
>
> *Ms. X (positive): I think that's the key word, getting involved, advice for other women...*
> *I mean, we're lucky, we've got a good family with a lot of support.*
> *Just find support.*

*Because it's not something that someone should have to go through alone.*

## Risk Perception and Action

Through the process of genetic counselling and testing, individuals are given a variety of numerical risks of developing breast or ovarian cancer. However, how individuals actually perceive their risk and what they choose to do about it differs, depending on a range of factors, not the least of which is the individual's personal experience and the biomedical information that they were given. Since all the women interviewed are given risk information in accordance with their test results, it is useful to examine the way that they perceive their risk and their following actions within those original biomedical groups: those with negative and positive test results, and those who were ineligible have testing.

### *Negative Test Results*

Women who were shown not to carry a BRCA1 mutation are fairly uniform in asserting that since they feel their risk is lowered, they no longer worry about it much. They felt their personal estimates of risk before testing were quite high. This was influenced mostly through the personal experience of seeing so many people in the family develop the disease. Not surprisingly, then, those who received negative test results were quite relieved to discover that they had a 'lower' (than they'd thought), or normal risk, particularly, when an individual shared many personal characteristics, such as body type, with a family member who developed cancer.

> *R: So, when you ended up testing negative, how did that...?*
> *Ms. U (negative): Well, then I thought I was ... sweet.*
> *I wasn't going to get this.*
> *I sort of had an attitude for awhile, that, oh, I can't get cancer now. But then you know, you have to get rid of that, because you can still get cancer whether you have the gene or not, you know? But, it's sort of; it's like a*

> *different set of values on it. You sort of think, you're never going to get it, you know? At least not ovarian and breast, anyway, you can get something else.*
> *... Before I saw it very high, because my mom died of it, all her sisters died of it. And I was like my mom; I've always had the same illnesses as her, everything. So, I thought for sure I was going to get it.*
> *Now, I sort of, I don't consider myself free of it, but I consider it way lower than what it was before. Moderate, I guess. I do go and have checks, but I don't do it as often as I did before. I'm sort of lazy now.*
>
> *Ms. T (negative): Well, before testing I thought it was 75% I'd have either [breast or ovarian cancer]. Well, I have [my] ovaries out; so, I'm, you know, because it's so much in the family. And now, I think I'm in the normal range, just one in nine, so I don't know what odds that makes.*
> *I always live a pretty healthy lifestyle, you know? No smoking and all that sort of stuff. ... You know, I know I can still get breast cancer, it's not that, I don't think I'm never going to get it now, I know, but it's just a normal risk like everybody else, not that high risk.*

Their normal risk subsequently allowed a reduction in vigilance on their part. Nevertheless, they still have the ordinary 1 in 9 chance of developing breast cancer and continue the mammograms and breast self exam recommended for the general population. Some mentioned that because the possibility of getting cancer had been in the back of their minds for so long, they had already made lifestyle adjustments towards a more healthy lifestyle (diet, exercise, breast self exam). They had no intentions of giving these up now that they had been informed their risk was not higher due to heritable cancer. Mammograms and being examined by a physician were still felt to be important, but only as much so as for the average woman. While none of the methods of early detection are perfect, the general consensus was that it was best to use all the available tools.

> *R: Now that you've found out you don't have the gene and your risk was normal, down to the one in nine, do you find you've changed how you think or how you do any of these things?*
> *Ms. T (negative): No, because it's part of your lifestyle now. I mean, I wouldn't stop going to have screening and stuff. I still go, still do breast*

> *self exams because that risk is still there. But it's, it's just part of your lifestyle. Now it's too late, you would never change. Like, I would never go out and say, oh, I'm going to go out and smoke and drink now.*

> *Ms. U (negative): I think they're [screening methods] very important. I do. And you should go regularly if you have cancer in your family. Even I should be going regularly, but I don't, because I think I'm free of cancer and I'm not, probably.*
> *But, I think they can also show wrong things.*
> *Because my sister got a mammogram before she had her mastectomy, and they said nothing is there and then when she had the operation, they found a huge growth, big as an orange, that was malignant. And the mammogram never even showed it, so ... And they said it has to do with whether you have dense breasts or whether you don't. And our family seems to have the dense breasts that don't show lumps. [But], I think, you should, because one time it may show it. I think if you catch it early, it is curable. If you catch it early.*

Prophylactic surgery, as an option, was still mentioned by this group, but in the past tense. Something that had been considered based on worry or a physician's recommendation in the past. Also, since relatives had undergone mastectomies (prophylactic or not) or oophorectomies or wanted to, many women had an opinion on the subject. This type of surgery often had a significant and personal meaning, sometimes even an association with death.

> *Ms. F (negative): And, so my decision [before being genetically tested] was that I would go with the checkups, that kind of thing. But there was no way I was going to go with the bilateral, because it's, oh, I hate operations. But it's just so final, you know what I mean? And, I think I would really want reconstruction, the whole bit at the same time, because I am married.*
> *And, I can remember how extremely ugly my aunt's chest was after mastectomies and then the radiation. It was sort of like a ... I mean, [an aunt] I took care of, just before she went into hospital to die. And this was over Easter holidays and her husband was working, couldn't get time off.*
> *So, I took care of her. I would have been sixteen, grade eleven at the time, and I can just remember the shear ugliness of this horrible, horrible, horrible disfiguring scar that she had and also the fact that she just, she must have been down to 86 pounds. I could actually carry her.*
> *So, that's still very vivid in my mind.*
> *So, I'm not ready for that quite yet.*
> *Hopefully, I have a few years yet.*

> *But, no, I was not prepared to do double mastectomies at that time, just based on [a physician's recommendation about suspicious tissue].*
>
> *Ms. U (negative): Well, if I was positive, I was ready to have a mastectomy and everything. I was ready; I was going to do everything. And I was going to, I guess, make sure I had my will and stuff, you know, stuff like that, that I could think of.*
> *It's sort of stupid, but you do.*
> *And I still have my ovaries and I would have had them out, too, by the way.*
> *R: You just said that people should definitely consider a hysterectomy and then with the breast cancer, either screening or a mastectomy. Is there a reason why you think that it's more important to have the hysterectomy than the mastectomy?*
> *Ms. U: No, I think they're both crucial.*
> *But some women, they won't have a mastectomy unless they really, really have to, because it sort of deforms their body, I don't know. But a hysterectomy's different. It's inside and nobody knows, sort of thing, you know? A lot of people are, I don't know, feel funny having that done. And I think I would too. More people are apt to go have a hysterectomy than a mastectomy when there's no real evident reason, you know?*

### ***Positive Test Results***

Those who receive a positive test result indicating a genetic susceptibility for breast and/or ovarian cancer are considered to have a high risk of developing cancer, even if the question of precisely how high a risk they have is difficult to answer. The medical options they are presented with are being followed in a high risk surveillance clinic in Vancouver, or possibly removing their breasts or ovaries before a cancer might develop (prophylactic mastectomy or oophorectomy). Alternatively, women may choose to modify their lifestyle or employ other non-medical strategies to try to lower their risks in their own eyes, if not that of the medical community.

Women's feelings of risk with a BRCA1 mutation are connected to how they feel about their various medical options. While all are aware that they are at a higher risk, what effect it will have on their lives and their bodies differs from woman to woman.

The range of risk to develop breast cancer specifically, that is given by the genetic counsellor is 50-85% over her lifetime. Either end of this range can be focused on, depending on what they feel a responsible course of action is with regard to their health. The concepts here are inextricably tied to actions.

Opinions about risk, screening, and surgery among those who received positive test results are divided into two groups: those who consider screening adequate and those who prefer surgery before cancer is discovered. There is a high risk surveillance clinic in Vancouver that provides breast and ovarian cancer screening by oncologists every six months. For many who learn they carry a mutation, this is a perfectly viable option and one they feel secure with. This group considers prophylactic surgery to be a radical option, given that they may never develop the disease. They tend to focus more on the positive side of susceptibility, that there is a chance they will never get cancer. In addition, the issue that having surgery cannot completely eliminate risk is discussed, since there still could be some potentially cancerous cells left behind. As with the negative group, physical similarities or lifestyles to individuals in the family who did or did not have cancer sometimes affected risk assessment.

> *Ms. P (positive): I see my risk as increased now.*
> *Before, I honestly, you know, I knew my mom had had cancer and obviously my sister, but I never thought about it for myself much. I'm probably the only one in my family, in my sisters, who takes more after my dad. So, I sort of have a different body type than them. And they're all very well endowed and I'm not. And so, I always sort of thought, oh, I would never get anything like that. And like I said, I'm quite into exercise and they're not and I just always see myself as being very different than them. So, even when we were getting the testing, I thought I bet I won't carry the gene and they probably will. You know, so, it was quite eye opening that yes, I carry this gene and my chances are probably as great as theirs, you know.*
> *But I don't see breast cancer as death. I mean I know it has and I've read a lot, believe me, but I've also read a lot where women have had breast cancer and ten years later they're still kicking. And I'm involved in running*

> *a lot and, of course, I go to the breast cancer run every year. And, I mean, half of those women out there all had breast cancer and they looked pretty darn healthy to me.*
> *So, I don't see it as the end of life. So, I'm not that concerned or worried about it.*
> *I mean I know it will be horrible if I get it and I would never wish that on myself or anyone. But, I know also that I would deal with it and hopefully live on and enjoy a good many years after that. When I see my sister, I know she went through a very difficult time for, you know, just over a year. But now she's looking great again and if you didn't know that it's happened, you'd never guess.*
> *And so I know that I've read the studies that say that your immune system is much, much stronger if you think positively. And I feel like I do that, like I, I'm almost naively positive, like I think, this isn't going to happen to me. I really believe that.*
> *I mean, I also believe, as I said before, that if it does, I'll cope, you know, and we'll deal with it when it comes, but I'm not going to worry about it. And at this point, I just think, you know, I don't have it, I probably will never get it. So, I think that's one way that you can sort of, by not worrying about it, I think that helps.*
> *I found it interesting, actually, when I went to the cancer clinic in Vancouver last summer and we sit and wait in this little waiting room before the doctors see us. And there was a girl with her mother in there who was quite upset. And I guess she had just discovered, obviously she was part of the study, too, and she had just discovered that she carried the gene. And she was very seriously considering having her breasts removed as a preventative measure.*
> *And I just thought to myself, you're crazy. You may or may never, get this. Why would you go and have fairly severe surgery done when it might not be necessary?*
> *Because my feelings are and from what I understand, and I said this earlier, is just because we carry the gene doesn't mean for sure, we are going to get cancer. And that's been proven and [the genetic counsellor] made that very clear. So, I think that's something that you can hang onto.*
> *I mean, I'm not that worried about losing my breasts. It's not that, I just, I just think you should leave well enough alone. And the very fact that we're going in and having this testing done regularly, we're going to be detected early if we do develop cancer, so. To me that's prevention enough. And then if you decide to have a radical mastectomy, that's maybe a good choice, who knows. Depending on the type of cancer that you develop. But having it done prior, it just seems really nuts to me.*

A perception that screening was the best option was particularly prevalent in young women. Not only could cancer not happen at all, but also if they did develop cancer it probably would not be while they were young. Screening, therefore, was definitely adequate for now.

> *Ms. X (positive): Just to go in and get the mammograms and to get tested and to know that ... I mean, even know, because it does happen in menopause, between now and then is a long time. A lot could happen, throughout that time.*
> *And they're going to know my body very well, right? So, if anything does happen, then they'll catch it, quickly. And it's also not as, for me, I mean, I'm sure it seems like my being a part of it isn't really relevant at this point, but they could find something along the way, so...*
> *I'm personally not too worried about it.*
> *It's not something that I think about every day.*
> *It's not something that worries me because of the one main fact that, apparently, nothing really happens until you hit menopause, anyhow, right? Or around that stage. So, if anything, I've got time.*

In contrast, some see their risk towards the higher end of the spectrum. They feel that surgery is necessary to reduce their risks, since screening merely detects cancer early; it does not prevent it. They consider themselves proactive in reducing their risk of cancer and consequently reducing their worry about it. This group is more likely to point out that they have an 8 to 9 chance out of 10 of getting cancer. In addition, some women felt themselves to be more likely to develop cancer because they were post-menopausal. Close family experience with those who had developed breast or ovarian cancer, particularly with family members who had cancer at a young age or who died from the disease seemed to increase the perceived risk a woman felt she had. Personal experience of having close family members develop and die from cancer, therefore appears to have as integral a part to play in risk perception as does information (percentages, etc.) received from genetic counsellors and other sources.

> *Ms. H (positive): Well, I was in the general population, if not slightly higher risk [before testing]. And now, I have 85-90% chance of getting cancer, or I had [prior to surgery]. So, it's like a 160-degree turn. And actually, I*

*would say, that my risk of getting cancer, having the gene, without surgery, I would say was probably 100%.*
*I don't have any doubt that whoever carries that gene gets cancer, at least in my family, this mutation, [is] very strong.*
*So, in my mind, it was a matter of taking care of it now, when I don't have cancer, or taking care of it when I do have cancer and having to add chemotherapy and radiation, plus the risk that maybe I didn't get it.*
*I looked at screening and for a long time, I thought that I would maybe think about screening over the long term. But I decided that I didn't want to wait till I got it. It came down to the same thing. Mastectomies do not eliminate the risk, but, as I said to somebody, they level the playing field.*
*I mean, you go from 85-90% chance down to 5-6%, which is better than the general population, actually.*
*So, I think that people...*
*There was a lot... the other thing that was out there when we found out, was there was a lot of negative emotional press to prophylactic mastectomies and for one thing, anybody who doesn't have the gene shouldn't even be commenting on it, as far as I'm concerned. Nobody has any alternatives to offer that can actually reduce the risk that significantly.*
*And I know that personally, since I've had surgery, it's not on my mind, it's not there.*
*And also, also because I know that, you know, I've had surgery, detection is easier because of the kind of surgery and that I have done everything that I could do.*
*If I had cancer, I wouldn't care how early they found it, how many cells there were, I would have had prophylactic mastectomy, but I would also have to have chemotherapy.*
*It's just a very invasive cancer that hits young women.*
*And I, so my choice was prophylactic mastectomy before I got it or mastectomy after I got it.*
*Either way I looked at it, I was going to be having bilateral mastectomies, so, better to do it on my terms, I think.*
*Those sorts of decisions I made, so it does in the scheme of things, up until I had the surgery, it was something that sort of made you think about things daily, if not weekly, later on.*
*Because you knew it was just a matter of time.*
*And actually, I didn't completely relax after the surgery until the pathology report came back a week later. Because up until then, there was still a chance there was going to be some minute cell.*
*Then, now, of course, the ovarian one is the thing to watch and, that's on hold too. I'll probably consider hysterectomy next year, you know.*
*I think, in genetic breast cancer, it seems to me that, early detection is more than the key. You know, it has to be detected very, very soon. I don't know why I feel that; I do feel like, you know it's more virulent in the younger women. [The genetic counsellor] says it's maybe because younger women aren't paying that much attention and it gets missed.*

> *I don't know that, but ... And there is no guarantees that, even if [they] get it early, early, early that a few cells haven't escaped.*
> *And I think that women with BRCA1, or any of the genetic things, should be offered, you know, I saw my oncologist every six months and I think that should be offered, if only because it gives you that feeling of security that somebody else is checking you too.*
> *There's a lot of emotional nonsense out there that can really, sort of, frustrate you and make you angry. For instance, I've had implants done for my reconstruction, because I couldn't afford the recovery time from the other one. You know, I don't, I have young kids. And, the garbage that's out there right now about implants, and I'm not saying it's not valid. But what I am saying is, it's all emotional.*
> *If you listen to the news, they're horrible, they're poison, they're this, they're that, they're you know, blah, blah, blah and women shouldn't go anywhere near them. And I don't need to hear that kind of nonsense, you know?*
> *I know in my mind, I've looked at them, I've reviewed all the literature, I've talked to my plastic surgeon, my surgeon, and tried to decide what was out there and what all the data said, so I've made up my mind. But, hearing that also, sort of makes you second guess yourself consistently. And I would say that's the problem through this whole process with the genetic ones.*
> *We went through the same thing when we started considering prophylactic mastectomies. At that time, people were just horrified. A lot of people still are, that you would, you know, mutilate yourself. But, I think that's grossly unfair and inappropriate because what is it saying to the women that have to have them?*
> *You know, they didn't have a choice and you're telling them, you know, if you don't really have a choice, I suppose you can go ahead and mutilate yourself, but if you have a choice, you shouldn't do it.*
> *And those people, I would say, I would describe my risk of cancer as being, I have a 9 out of 10 chance of getting cancer is what I have and you tell me, what would you have me do?*
> *And most people that are reasonable would say, there's no choice.*
> *But, so I get really angry when I see a lot of the emotional stuff out there, and that's why I say people to don't have these genes shouldn't comment.*
> *I was very pleased, [a prominent physician], at that time came out, he was the only one, and he took a lot of flack for it, came out suggesting that prophylactic mastectomies might decrease your risk of getting breast cancer for genetic.*

While some who received positive test results felt more strongly than others that surgery was an important way to lower risks, everyone felt that screening was important. As in all the groups, positive, negative, and ineligible for testing, there is a recognition that screening is not perfect. It was still seen as essential, especially for those who had a stronger risk.

> *Ms. N (positive): Instead of just being like the normal populace, where, you know ... And because again, we're pre-menopausal women, we're still fairly young. Most women don't get breast cancer until maybe mom's age, like 60. And, so, recognizing that we have a higher risk, it's kind of difficult when you recognize that mammograms don't really work in younger women the same.*
> *And, recognizing that there isn't, unless you feel a lump, like [my sister] did, there isn't really any other way of knowing.*
>
> *Ms. H (positive): Well, the most important thing to me at that point [right after getting positive test results], was information and also to know that I was being screened, carefully, by someone other than me. It really helped me to go to see an oncologist, both of them, because I knew that chances are if I missed something, they're going to pick it up.*
> *Mammograms, I know there's a big controversy out there about mammograms, but frankly, when you're in a group, a population where you have an 85-90% chance of getting breast cancer and everybody you know in your family, or there's a lot of women who have the gene that have got breast cancer and have died of it, you need to use every single solitary tool, regardless of what the, you know, the studies show.*
> *You have to use every single, solitary tool that's out there, because there's not many.*
> *And the same with the ovarian cancer, which is even harder to find.*

### *Ineligible for Testing*

The risk perception of those who participated in testing for BRCA1 could be grouped fairly clearly into coherent collectives of opinion. By contrast, those who could not participate in testing were the most diverse group in their opinions on risk, surgery, and whether or not they had enough information about their status to make adequate health choices. They were given an estimated risk, based on their family history, from epidemiological tables. However, this information is interpreted differently by different women, depending on what their preconception of their risk was, and this, in turn, influenced what they do. For some, percentages are seen as somewhat ambiguous compared to finding out whether or not they have a mutation. Their choices, therefore, take on more of an aspect of guessing than do those of the other groups. Screening and surgery are often available to them, but can require convincing a physician that their concerns about cancer risk are valid, since they fit less easily into defined medical categories.

Those with a strong history of ovarian cancer and some others have enough concern about their risk to want surgery after they finish having children. This is largely due to difficulty in detecting ovarian cancer. Others were concerned about the idea of doing prophylactic mastectomies without the information that they had an inherited gene mutation or more information about the efficacy of the surgery itself in preventing breast cancer.

> *Ms. R (ineligible)): I mean, I'm quite young and my mom did die and I was there with her for the whole thing, so. And I realize that there's more chance of getting breast cancer, because of being on the estrogen and all that. But, I think it's easier to find breast cancer than it is on the ovaries. You may get it; you may not get it, you don't know until it happens. And with ovarian cancer, the scary thing is that you can be dead in three months.*
> *I mean I realize just because my mother had it doesn't mean I'm going to get it, but, I still felt that 9 chances out of 10, either me or my sister's going to get it. You know, I just felt that way. I think the more you worry about something, the more chances you're going to get it. And I was bound and determined that this [wasn't] going to happen, I was going to have my ovaries out. I mean I, ever since I was 18 years old, I decided that, by the time I'm 25 they're coming out, that's it, that's final. And I, it sort of stretched a little longer.*
> *And then when I went to the genetic clinic, I guess they sort of, try to dissuade you from it a little bit. But, it was just my ovaries. It wasn't like I was going to have my breasts removed. Or a limb cut off or anything like that. You know, it didn't seem as drastic to me as other things.*
> *Get rid of them and be done with it. I mean, I'm pretty for preventative measures. I think it makes a big difference in how you perceive yourself and how you feel...*

> *The other situation with [my sister], she isn't quite as worried about it. You know, she's not as worried about having ovarian cancer and dying of it. I was four years older than her when my mom died and I was with her a lot.*

> *Ms. J (ineligible): You know, it made both of us just cry right in the office [many years ago], to say, you know our sister just passed away three or four months before and [the surgeon's] telling us, well we should definitely get bilateral mastectomies.*
> *And to me, my whole argument with that is, you can never get all the breast tissue. And what I had asked them in Vancouver was, what has there been done with the people who have had it? Has there been any occurrence with breast cancer, anyways? But, they hadn't done a study on it, so they didn't know and he had never, he personally had never heard of anybody, but that was my argument.*
> *R: Right.*
> *Ms. J: I think some people that I've, you know, read about that they, within their head, by getting a bilateral mastectomy, they were doing something extremely positive, they were cutting off that chance. That's what they needed to do. And, that's fine.*
> *R: So, you would have just liked to have had more information, then?*
> *Ms. J: Yeah, yeah, more information. But, you know, I know studies, they take time and they cost a lot of money.*

Others find a great deal of reassurance in discovering that their risk, represented by risk table percentages, is less than they had guessed it would be from their own interpretation of their family history before seeing the genetic counsellor. With an increased degree of screening, perhaps seeing an oncologist once a year as well as their GP, they feel confident that they are doing everything they can for themselves.

> *Ms. A (ineligible): And yes we are in a higher risk category, but not as the figures that people see coming out in the media and in various forms, you know. I believe not, anyways. And that's fabulous, that's fabulous, reading you either have it or you don't, or you're going to get it or you don't, and if we do have it, you're likely to get it a little more obviously than if not, but not necessarily For me it was good news.*
> *To hear that we're not in the more than 50%, like 65%, you know, we have a 65% chance of . . . or higher, is what we've been hearing for years and years and years and it's really not [that high a risk]. I think that's what I got, ultimately, out of it.*

> *Ms. K (ineligible): You can't pin it down. You can lower the percentage of risk, maybe, maybe, and that is if it makes you happy to think that, you*

> *know. It's nicer to think that you only have 12.35% chances of developing rather than 95% chance, but even in that 12% chance, I may still develop it, anyway, so. I just accept that, you know, I do what I have...*
> *I can't do more than I'm already doing right now. So, I do my self test, I do, I see my doctor once a year, and I just saw a breast specialist and he agreed to see me once a year. So, I see my GP in six months, and then six months later, I see him. So, I guess I see someone twice a year.*
> *There's not much more I can do.*

Still others are concerned that they do not have enough information to be making good decisions and wonder if they should be pushing for more care. They may also be troubled by finding out that testing must begin in a living affected family member; if all affected relatives are deceased, testing is not possible unless someone else in the family is diagnosed with breast or ovarian cancer. In some cases, they feel they are not taken as seriously by medical professionals as they lack the status of having a 'strong risk'.

> *Ms. Q (ineligible): Given that we only have one person in my family who's had breast cancer, that I'm not considered high risk by them. But then I said, she's the only one in the sample. We don't have any other siblings, nothing. And her mother died when she was born, so we just have, so in a sample of one, that looks to me like it could be high risk, it depends. And then she told me about the screening program that they have there. And that I could get into that, but, I had to wait so long, because I'm not high risk. So, I just entered that about two months ago, a month ago. But, you know, I wonder if that's enough.*
> *Because it's such an art detecting breast cancer, it's not a science, okay?*

Screening was considered to be very important by those ineligible for testing, similar to those who had gone through testing. Mammography and other tests were seen as worthwhile, even if they were uncomfortable or if the women were a little worried about the radiation involved in mammograms.

> *R: What do you think about screening practices like breast self exam, breast examination by a physicians, and mammography?*
> *Ms. G (ineligible): It's a must.*
> *We're very lucky to have mammography in this country. You know, free, well, not free, but you know what I mean. To be at our disposal, luck enough to do it.*

> *I wish they'd invent something more pleasant than a mammogram, though. I'll tell you, if it was a guy, they sure wouldn't have that kind of a test for a guy. Yeah, we're going to put this in here and squeeze it as tight as we can. Oh, sure.*
> *I mean, if they can put people in outer space, I don't see why we can't have a better test than that.*
>
> *Ms. J (ineligible): And, I'm a little leery about mammography, because of the amount of rays that you're getting. Like, the year that I missed my mammogram was the year before I had an extra picture or two taken and that really bothered me. And I felt, maybe I moved or whatever, but I just felt that the technician who was taking care of me, she was a different girl than it had been for three or four years and that she seemed a little bit green to me. And maybe if she was that green, maybe she should have had a more experienced person with her.*
> *But, you know, I think the self examination, you know, we can all do that for ourselves once a month. And, you know, for the ladies who, whatever the regular age is, forty, over forty, or whatever for most of the population, they should get it done and then, people who are more high risk, however often their doctor suggests, I think it's very important.*

### *Cancer Prevention*

All who were interviewed felt that you could not completely prevent cancer, although you could decrease its seriousness by detecting it early. While lifestyle was discussed somewhat, the role of chance or fate was also touched upon. A common discussion among all groups was the fact that one could never really predict who would get cancer and who would not. This was borne out by the lives of friends, family, and acquaintances. Lifestyle was only felt to get one so far towards staying cancer free.

Nevertheless, others placed more emphasis on lifestyle, if only because it was something they could control, and participants claimed that it had good general health benefits that would also be useful against cancer. In addition, having a positive attitude was felt to be an asset, either to prevent cancer or help fight it better. However, moderation in lifestyle was also stressed as important. There was skepticism concerning diet fads and other extremes.

Only one person brought up the role of food additives (preservatives, etc.) in causing cancer. Wider ecological concerns (pollution, radiation, etc.) were rarely mentioned in general conversation in response to the question about whether cancer could be prevented. However, ecological concerns were not specifically targeted in the interview, as lifestyle was. While most people could discuss the two-hit theory of cancer causation, where two copies of a gene were mutated so that they were no longer able to prevent cancer, there was little discussion of what mutated the genes or caused the cancer itself to start.

> *Ms. F (negative): [Testing] has actually not changed anything. I still know that I'm at risk, especially as I get older, of getting breast cancer. So, it really has had no effect, whatsoever. Because my grandmother obviously must have carried the gene. Well, she died in her eighties of stomach cancer.*
> *You know, my mother who smokes like a chimney, drinks coffee, eats poorly, but is extremely physically active now, she's going to be 79 next month. She's never been sick. I mean, this is one woman who should have cancer, just because of the smoking. But, you know, it just seems to be, I think it's in the cards, either you're going to have it or you're not and that's the way it is.*
>
> *R: So, do you feel that cancer is something that can be actively prevented then?*
> *Ms. A (ineligible): Absolutely not.*
> *R: Okay.*
> *Ms. A: And why I say that is I think that we have a genetic disposition towards it. We either are going to have it or we're not going to get it, we're either going to help it along if we do have it, by poor eating habits, lack of exercise, or stressing out all the time or whatever. Or our biological, you know, ability or immunities to fight off infections, or whatever.*
> *Again I could, I think I could sort of synopsize it by saying that I believe if we have a predisposition towards that and we don't look after our health and our stress level and our diet and our exercise levels and this and that, that we might help it along. But I don't believe that just by doing that you're going to prevent it. It's the same with alcohol or having children at a young age.*

*My eldest sister [who had breast cancer] had four children by the time she was twenty-eight, starting at 19, or something like that. And we were under the impression that having children at a young age would help and not being on the birth control pill, etc. And not drinking. Well, my sister never drank, she never smoked, she wasn't overweight, she might have had a little bit too much fat intake, in the way of meats and sauces and gravies, but basically a healthy diet, not junk food. She might have been ten or fifteen pounds overweight, but not fifty.*
*And I believe maybe there's a difference between the pre-menopausal, it's so aggressive, it doesn't really matter what you do. Maybe later on in life, with the more common aging postmenopausal cancer all these things will make a difference more, as to how well our body can fight off infections and cancerous mutations.*

*R: Do you think cancer is something that you can actively try and prevent?*
*Ms. O (positive): Yeah, I do.*
*There is, there is a certain part that you can't. There is a chance that it's going to happen anyway. But taking care of your health in different ways, through reading and hearing what the doctor has to say also, taking care of your body as far as exercise and what you eat, how you take care of things like that. They have discovered that it gives you a better chance.*

*R: So, what do you think then, about the effect of diet and exercise, and vitamins and that sort of stuff?*
*Ms. Y (positive): I actually believe that with life, have moderation. You can't, like I just for my own self and my family, how we basically approach life is, I don't believe that, you use vitamins and you exercise and you eat alright, and you stay away from all that, that you're going to end up healthier than the guy who eats all that and doesn't exercise. I just believe in moderation.*
*You can't eliminate things.*
*I mean I do, I see them as being important for your overall health. I can't see, I don't specifically think that taking vitamin C is going to prevent me from getting breast cancer, from developing breast cancer. No. That I don't. But I can see that taking, having the adequate amount of vitamin C is good for you in general.*

*R: So, what do you think of the effect of things like diet, vitamins, and other similar, exercise, on the development of cancer?*
*Ms. Q (ineligible): I don't ... Like, I think it's probably a small variable, but it's one ... I mean, for me, anyways, it gives me a sense of control. So, does that have a psychological effect that's important? Maybe, you know.*

*R: Do you think cancer's something you can actively prevent?*
*Ms. T (negative): I think part of it you can. I think stress has a lot to do with it. And I think if you're not worried about catching it all the time,*

> *maybe that would help prevent it. I think a certain amount is, I don't know, all of a sudden the cells take a notion to grow, I don't know why they do that, but ... I think stress and lifestyle makes a difference.*

> *Ms. D (ineligible): I think, that as we go along, you know, we're really trying not to have our heads in the sand. Whereas, I think our mom really had her head in the sand after her mom passed away. Her mom was still quite young as well. I think, late 40's or early 50's. After her mom passed away, we were told by the rest of our family that my mom just accepted the fact that she was going to die of cancer. She just knew that. And, I think that's half the battle, right there.*
> *So, I think she gave in to it way too easily without being educated about it. That's why I feel we have a much better chance, the more educated that we are. Either, the easier time we'll have of it if it does come around to us, developing cancer, or in a preventative sense.*

> *Ms. J (ineligible): And a really good outlook, stay as positive as possible. Because I think ...I know there's a lot of old, really negative people alive, but I think you just have a better chance if you have a good outlook.*

### ***Cancer Hopes***

Several people placed hope on future medical development to alter the mutation or otherwise prevent or cure cancer. Research, and genetic research in particular, was mentioned as the way to do this. It provided a strong motivation for participating in genetic testing research in the first place.

> *Ms. T (negative): And I hope for my niece's sake [who received positive test results] that they're going to do genetic engineering that can change that gene a little bit, you know, because she's young, she's only 21. That's what I told her, she says, well what do you think? And I said, I think you're really lucky and I said, they know about you, so if something comes up, who're they gonna call? They're going to be calling you. They can do so much nowadays, you've got a fighting chance here.*

> *[Ms. O & Mr. X, both positive, daughter and father]*
> *Ms. O (positive): Well, when it was suggested, by all means, and of course it's also approached to you in the sense that it is to, it's for knowledge around cancer, you know.*
> *It's ...*
> *Mr. X: Cancer research.*

*Ms. O: Cancer research, and you think of all the people that suffer out there and having two members of our family already, gone through certain amounts of, you know, that are close immediate family here. You know, it's just, of course, we'll do whatever we can, you know.*
*And also another benefit is maybe, they'll learn enough through this gene, by the time our kids are around our age, when they'll be more susceptible to the cancers, that they'll be more answers.*
*Mr. X: Maybe a cure by that time.*

# Chapter 5: Discussion

## Cultural Trends & Social Factors

### *Information, Culture, & Identity*

A central recurring theme in the interviews was the value of information gained through genetic counselling and testing. What individual women actually did with the information they gained through the counselling and testing process varied, but the information itself was almost always considered to be a tremendous benefit. This theme is important to understand the women's overall satisfaction with both genetic counselling and testing.

Information given in the counselling sessions about risk, mechanisms of hereditary cancer, the test itself, and basic scientific information about genetics, were all mentioned as useful. Similarly, information about medical options was highly valued. Counselling and test information was felt to lead to several positive actions or attitudes. A sense of closure, or at least control, over worries about family history could be achieved. Women felt the information gave them control of their own health and increased their ability to make good "solid" decisions based on objective facts. Information is important: it is an avenue to improve women's chances to live longer lives. It is a way to make a choice with facts behind it, and knowing is better than not knowing, especially with a strong family history of cancer.

The concept that 'knowledge is power' is strongly present in the interviews. The benefits of information go beyond the data provided, because it enables action. Knowing your risk factors is supposed to improve your ability to make decisions and fashion your life. Knowing gives a sense of control.

Such a theme is consistent with Gordon & Paci (Gordon and Paci 1997) who discuss an autonomy-control narrative, centered on information and self-determination, which they claim predominates in the USA. The Canadian women I spoke to appeared to hold similar conceptions of how to achieve good health. Gordon & Paci (1997) suggest that knowledge is essential in order to create options for choice, and choice is fundamental to self determination, which is seen as a central value in North American society. The findings here heavily support the cultural pattern described by Gordon & Paci (1997). This desire for knowledge, in the context of genetic testing, in order to make good choices and improve one's future, should be understood within a wider cultural script which indicates that knowledge is a good way to deal with danger, maintain control, or cope with suffering. These women, then, are following a cultural directive to aid them in dealing with their circumstances. The autonomy-control narrative helps explain why the technology of genetic testing for cancer susceptibility has such meaning for those who wish to have testing, and why they feel the benefits of the technology outweigh the disadvantages.

This wider cultural context also helps to explain why the desire for knowledge has a companion need for a corresponding action arising from that knowledge. Gordon & Paci describe the autonomy control narrative's primary reality as material. This is manifested in a bias towards action. It is important for the women to be doing something, often something tangible, for example, going through a diagnostic test, or using the latest technology.

A combination of the search for knowledge about cancer and risk, with the sense that knowledge should lead to action, are key components to these women defining themselves as "proactive" without being "unhealthy", which implies an unproductive obsession with cancer. Many women mentioned that they like to be active, or proactive about their risks, rather than 'having their head in the sand'. Action, doing all one could for oneself, was arming oneself with information and using the medical support that accompanied it. To be as proactive as possible meant that one would have nothing to reproach oneself about later, even if cancer did develop. A good lifestyle, although felt to be only of minor importance in causing breast and ovarian cancer (in agreement with the biomedical view), also played a role in helping a woman feel she was creating the best chance for herself, and therefore leading to a more positive, proactive self-image. Similarly, though, it was important to approach lifestyle in moderation and not obsessively.

In addition to providing information, genetic counselling provides a communication style valued in professional-client relationships. The communication by the genetic counsellors was viewed favorably, because they provided a comfortable atmosphere addressing concerns and answering questions. In the USA, explicit communication is preferred, and discussing or labeling something helps to control a problem (rather than keeping emotions "in", which is seen as destructive) (Gordon and Paci 1997). It is understandable why most women in Canada would be satisfied with a genetic counselling experience, under a similar autonomy-control narrative, since counselling provides explicit communication on a feared topic.

Hope and a positive outlook towards the future, which were prevalent in these interviews, further set the general cultural context for genetic testing. Many placed hope on future technological advancements in order to remove the danger to themselves, their children, and other relatives. This follows if, as Gordon & Paci (Gordon and Paci 1997) suggest, change and growth are important goals with regard to the future and the future holds promise of better times. In medicine, this means hope in technology and bio-scientific research and is epitomized by the use of and faith in experimental therapies. This is also in accordance with Del Vecchio-Good's work (Del Vecchio-Good et al. 1990), which emphasizes that the concept of hope is an important concept for cancer treatment and fundraising for future research in the USA, and, by extension of the work here, in Canada.

### ***Perceived Cancer Causes***

There is a strong prevalence of the biomedical view of cancer prevention and causation among those interviewed. Not surprising given family histories and media attention on genetic research, genetics is recognized as having a serious contribution towards cancer. Nonetheless, some point out that the risk for sporadic cancer for the average woman seems high. Apart from a few comments about food (such as preservative use) and exercise, environment is rarely mentioned. This could be due to the fact that the women were never asked any direct questions about the role that the environment played in cancer[2]. It could also reflect a focus on those aspects of life that they feel they have the most control over. In keeping with the medical literature (e.g.

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[2] Possibly due to the investigator's own cultural biases in deciding what was important to ask.

Pritchard, 1997), participants see screening as being very important, even if not perfect, while diet, exercise, and other unproven factors are less consequential.

Nelkin & Lindee (1995) suggest that the gene has become infused with considerable cultural meaning and powerful explanatory power, in the sense that genetics is focused on eagerly as a solution to problems, even in situations where causes are complex, multifactorial, and hard to determine, such as is the case for cancer. Environmental components can thereby be neglected as secondary to the role of genetics in individual problems.

Genetic testing for BRCA1 mutations provides a useful service. Genetic testing for breast and ovarian cancer susceptibility is important to these women. It may provide them with a more defined risk assessment, which provides them access to more vigilant screening procedures. There are distinct advantages within the medical system to having one's risk identified as high by a genetic test. Alternately, being assigned a lower risk allows a relaxation to the same level of vigilance as the rest of the population, which is also seen as a benefit.

### *Genetic Testing and Life Decisions*

Nelkin & Lindee's (1995) critical review of the gene's use as a cultural icon and a potential tool for shaping society raises the question of how much impact genetic technologies, like testing for hereditary cancer susceptibility, will have on those who have testing and society in general. Is it possible to have this kind of knowledge, as Rothman (1986) questions in the case of amniocentesis, without making large life changes, which in turn could affect societal structure? Will it, as Nelkin & Lindee (1995) suggest, make it socially unacceptable to bear children with such a mutation? What will be the impact on life insurance and employment?

As in any subject related to genetics (Jallinoja et al. 1998), there is little consensus between individuals in how great an effect they think this will have. In terms of deciding whether or not to have children or the necessity of surgical removal of the breast or ovaries before cancer develops, there is variation in how much impact individuals think genetic testing will have on their lives or the lives of their children. What one person views as a rational consequence, another sees as a drastic extreme. Since any societal change will have to come from the actions of individuals, the variation on these issues suggest that the long term consequences could be widely mixed. It is hard to say what long term effects there will be for insurance and employment discrimination, since these are largely determined by employment policy and how medical records are stored, for instance if they are kept confidential and separate from a person's standard medical record.

## The Individual: Embodiment of Knowledge: Risk Negotiation & Action

Individual differences are clearly present in estimations of risk and how much it affects decisions individual women make when it comes to raising families and how to live. Clearly there are some cultural influences which sway women towards testing in the first place and help shape its meaning for them. However, after testing, people make different decisions about what to do. How then, do individuals take the information they are given by the genetic counsellors as part of testing and translate it into their individual conceptions of risk and what is best to be done about that risk?

### *Negotiation of Biomedical Knowledge*

Rapp (Rapp 1998;Rapp 1988) and Lippman (Lippman 1999) both document ways in which individuals alter, challenge, reinforce, or negotiate with knowledge received from genetic counselling. The findings here show similar processes of knowledge negotiation.

#### Ambiguity

One way knowledge is altered is to make use of the ambiguity present in the scientific results. Women are often given a range of risk percentages and can focus on whichever end of the range they decide is most appropriate to their situation. This ambiguity can provide a percentage that can be both a motivator and a justification to action, since the action can follow the risk concept or the concept can follow the action. Rapp (1998) found that the ambiguity of medico-scientific results was used when women made decisions about whether or not to continue pregnancies after amniocentesis, particularly in the case of genetic conditions where the possible outcome was difficult to predict clinically. Lippman (1999) found that women recalculate what maternal age means statistically, to justify whether or not to undergo amniocentesis. Here, women question the necessity to take drastic steps (such as the removal of breasts, for example) given that no one can clinically predict that they will ever get the disease.

### Personalizing Statistical Risk

Another way that generalized risk was negotiated and personalized is by bringing family or direct experience to bear against the risk figures from the genetic counsellor. For instance, those whose family history contains mostly breast cancer will be less worried about ovarian cancer (and vice versa). Technically, the genetic counsellor tells them that if they have a BRCA1 mutation that they will be at higher risk of both, but women are generally most concerned with the cancer with which they have experience[3].

In yet other cases, the information the counsellor has given has not only been modified to fit with family history but is questioned outright. Implicit in this questioning of medical authority is the conflict between probability statistics, which are based on a large number of people and held to be scientifically accurate, and a person's estimate of their risks given their personal experience, or what people they know, such as family or friends, have experienced. For instance, one woman mentioned that the genetic counsellor made it sound kind of hard to develop cancer from a genetic susceptibility and paralleled this experience with remembering how, in biology class, they made it sound kind of hard to get pregnant, which did not parallel her personal experience when she and her husband decided to start their family. In another case a woman whose only female

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[3] Interestingly, science may simply be slow to follow their trust of personal experience here. There are indicators that different types of mutations in the same gene could result in a greater risk for one cancer or the other, but there has not yet been thorough enough study.

family member had developed and died of cancer, questioned the counsellor's assertion that she was still relatively low risk, since few people in her family had had cancer and therefore did not meet test criteria. She found it frustrating that her own conception of risk was not matched by the scientific estimate.

Personal experience, particularly with members of the family who developed cancer, is a very important part of decision making for these women. This is information that they have gathered with their own senses over a period of time, not a numerical percentage, subject to change with further research findings. Personal experience provides very memorable data on which to estimate one's risks.

This is similar to Lippman's (Lippman 1999) description of the pattern she found concerning amniocentesis, where fetal health is redefined according to personal experience with birth defects and what constitutes a healthy child. Rapp (Rapp 1988) also found that statistical information was mitigated by personal experience among women with family and friends who had many healthy babies without birth defects.

The speed of cancer detection and the mortality that accompanies it in women's personal experience appears to change what actions they feel are necessary for prevention. Part of this could be a generational change, related to progressively earlier cancer detection and better methods of treatment, resulting in lower mortality for younger generations. For instance, in this discussion between a mother and a daughter, it is possible to see how opinions can change about the threat of a hereditary susceptibility to cancer to life.

> *[Ms. W & Ms. X, both positive, mother and daughter]*
> *Ms. W: I mean, I think I had always had it in the back of my mind, just because of watching my mother go through it. I mean, we've come such a long, long way from almost 30 years ago, to when my oldest sister had it,*

> *almost 7 years ago. And then 3 years ago. And just at different stages, but, I think in the back of my mind, I had that I was eventually going to die of cancer. And I think, just because it was, that perception, that I was raised with. And, I mean, in the olden days, it was like, you're diagnosed, you're gone in 5 years, right? So, I always thought that.*
> *(Later in the interview, discussing her prophylactic mastectomy, which she felt was necessary, given her risk and her age.)*
> *Ms. W: No, and you have to grieve. I mean you give up a big part of your body, you know?*
> *Ms. X: But seeing you guys go through it has prepared me a lot, too. Because unlike you, you didn't see your mom come through it. And I've seen everybody come through, and it's just like, it's not a breeze, but just watching them go through it just makes it seem, like, oh, okay, not that hard.*
> *R: So, what do you think about surgery, generally?*
> *Ms. X: I'll cross that bridge when I get to it. It's not something I'll be glad to do. But it's something that I know I can. I really didn't understand cancer before all this happened. I didn't think of people actually coming through it. You know what I mean? I always thought of cancer as death.*

The ramifications of mastectomies, prophylactic or otherwise, are also different for different women. This, again, depends on what their personal experience is, as well as whether they prefer an intervention to decrease risk, or prefer to wait until such time as there is a problem.

## Counselling as Reinforcement

It is important to note that, while personal experience is important, women usually value the information discussed with genetic counsellors. Information is important and is included in their risk perception and what actions are perceived as necessary to reduce them. In some cases, the personal and the biological sources of knowledge can combine, such as when the test results provide a biomedical reinforcement of previously held views. For instance, if one supposes from family history that one has a high risk , this can be reinforced by a positive test result. It can therefore support steps taken to reduce risk that one was already contemplating before testing, such as the removal of breasts or ovaries, or an increased level of screening. Lippman (Lippman 1999) has also indicated that information from genetic counselling is used to confirm women's own claims.

### Modification of risk by Personal Characteristics

There was an underlying theme in some of the interviews that stressed personal characteristics or habits in relation to cancer risk. Despite the acknowledgement that cancer is unpredictable from lifestyle and other factors, certain personal characteristics were thought to moderate it. Body shape was one of them, either by body fat in general, or looking or not looking like the individual in the family who had developed cancer. Differences in the amount of exercise or diet between themselves and the person in the family who had developed cancer were also occasionally noted. Attitude was also thought to be important, whereby, a positive attitude was perceived as being able to help prevent cancer.

This theme is similar to that seen in Lippman (Lippman 1999), where women would personalize the amount of risk involved in maternal age. They would modify the risks of their numerical age by mentioning good personal habits that they had, such as exercise or good diet. This, then, set them apart from the 'average' or 'normal' woman of the same age and decreased the amount of risk their baby faced.

## ***Embodied Knowledge***

The women here negotiate biomedical knowledge gained through genetic counselling and alter it based on personal experience in a variety of ways. These include playing with ambiguity, personalizing statistical risk, using the information as a reinforcement of previously held views, and modifying risk by personal characteristics.

Such processes may be present in all instances where individuals are encountering genetic knowledge through genetic counselling. They indicate that interaction with genetic counselling always occurs through a lens of personal experience, particularly with respect to risk perception. The processes may also be used to negotiate with scientific information in a more general setting.

This negotiation of biomedical information and its combination with personal experience creates knowledge that is then used in everyday life and supports action. It represents a form of embodied knowledge using Lippman's definition (Lippman 1999), its very presence in action and everyday life representing its embodiment. As Strathern (1999) points out, the holistic concept of embodiment consists of moving conceptually from a 'noun-based' understanding of how people interact, such as abstract knowledge or information, to one where the abstract is incorporated into action, 'verbs', or "the being that resides in doing, that issues from and is expressed only in doing"(Strathern 1999)p. 202).

Thus genetic testing and counselling are incidents where a dialogue takes place between abstract biomedical knowledge and the knowledge provided to each of us by our own personal experience. In this case, the desire for genetic counselling can be understood as an attempt to actively seek out that extra component of abstract knowledge so that it can mediate the knowledge of the personal, not negating it, but striving towards an interacting balance of the two.

> *Ms.F: I'm just taking a look at this paper, I mean, you know, in black and white, you know there's no pain to it. You don't see any blood, you don't see ... You know, people have chemotherapy, or radiation and they're talking about the side effects, and they're having diarrhea, vomiting, and what have you and you think, on paper, there's no smell to it, there's no pain to it, there's no noise to it, there's no discomfort, there's no embarrassment ... I*

*guess, really, that's what you're trying to do with genetic counselling, you're trying to get it down in black and white, and this is what you're dealing with ... The emotional and the pain aside, you know?*

## Societal Trends and Individual Endeavors

There is an important distinction between the cumulative actions of a society or culture and the actions of an individual. Creation of meaning takes place at both levels and needs to be considered separately, although the two levels are, of course, interconnected. As a result what may be beneficial for the individual may not be so for society. This may be the case for testing for hereditary breast and ovarian cancer susceptibility.

It is possible, and perhaps necessary, to question the direction in which North American society's biomedicine is moving with research and treatment of cancer. The focus on genetics in connection to cancer, without a widespread attempt to look at the root causes of the disease can be queried. As Steingraber (Steingraber 1998) has reviewed, there is evidence of specific carcinogens and other structural and environmental connections to the causes of cancer. Yet there is a strong tendency in biomedical research and in the information provided to the possible sufferers of cancer to focus on genetics. This raises questions about the efficacy of current research and intervention policy, particularly given that hereditary cancer comprises only 5-10% of all cancer cases. Why is such information missing from public consciousness, funding policy for research, and the genetic counselling communication?

However, for those affected by hereditary cancer, genetic testing is very important. It provides an objective perspective on a suspected increased family risk for cancer. A test result indicating increased risk can give access to the best of what preventive and early detection options exist at this point in time. Genetic testing makes sense in this context for the individual. One gets forewarned, and thus can change lifestyle if one chooses and can have access to medical support. It represents a chance for advocacy and the best choice for control in an imperfect world. Furthermore, hereditary cancer testing is "doing something", which is important in an autonomy-control narrative dominant culture. By comparison, there are few practical measures dealing with environmental or structural causes of cancer, which can prove beneficial to a particular individual.

There is a conflict between the two levels of society and individual. To assert that more effort should be expended to address environmental carcinogens might imply that funding should be withdrawn from genetic testing and therefore the support of those with a higher susceptibility, leaving them vulnerable. Changes to larger structural and environmental causes of cancer would take a long time, which may not be something a person with an increased risk of cancer has. Genetic testing, for these individuals, represents something that provides benefits now. However, advocating a continuation of the current focus on genetic research does not address (and probably sidetracks attention from) those 90-95% of "sporadic" cases of cancer that occur.

It is important that hereditary susceptibility to cancer should not be seen as an individual's problem, rather than as an increased vulnerability to a problem that affects everyone. In order for genetic testing to not become a discriminatory process, perhaps more attention should be paid to the true basis of cancer; the cause of that second 'hit' in Knudson's model.

# Chapter 6: Conclusion

Women interviewed about genetic counselling and testing for hereditary breast and ovarian cancer susceptibility were generally very positive about their experiences. The information gained, coupled with the increased access to medical resources, was chief among the benefits perceived. Seeking out this information gave a sense of personal control and contributed towards a proactive self-identity. There are significant North American cultural patterns that shape the meanings derived from seeking increased information in the face of a threat. Such actions are linked to a culturally valued self determination.

Additional sources of information were also found to be important, particularly when assessing the nature of risk. Biomedical knowledge, while actively sought, was negotiated and combined with the knowledge derived from personal or family experience to create an embodied understanding of risk and the actions that accompany it. The two kinds of information create a balance, which allowed women a strong standpoint from which to make important decisions related to their health.

A broader view of cancer causes appears to be missing in this biomedically derived context. While no one can deny the important role that genetics play in cancer development, particularly in these individual lives, it is necessary to view genetic testing for cancer susceptibility within a wider context in which 90-95% of cases are sporadic. If justice is to be done in the long term to those who have a higher inherited risk of cancer, then more focus needs to be on wider environmental causes of cancer that make these individuals, as well as the general population, develop cancer. Otherwise, there is a danger that in the popular perception, cancer will be viewed as an inherent genetic defect about which little can be done.

Research and policy implications of this study include a recognition of the benefits of testing for the women involved, provided that those who have testing continue to receive a high level of counselling and medical support after testing. In addition, discriminatory effects as a result of testing (e.g. life insurance or employment) need to be minimized through some process of increased confidentiality or legislation.

There is an extensive cultural component to the perceived benefit of genetic testing and counselling that helps shape the meaning of this technology to the people interviewed. The presence of these cultural aspects suggests that the balance of benefits and disadvantages to this technology for those with differing cultural backgrounds may be different. It will depend upon the symbolic meaning of knowledge, choice, and self determination in any particular culture. Cultural differences can be powerful forces driving us towards certain types of knowledge and technologies. Further cross cultural research in this area is essential to help determine the global implications of genetic testing for cancer susceptibility.

In addition, cross cultural studies concerning disease prevention, and specifically cancer prevention, would give insight into how popular attitudes towards cancer causes and research policy are culturally shaped. This could aid us in understanding the prime importance North Americans place on genetics in cancer development. Further, the importance placed on genetics in cancer research should be questioned if it distracts from determining and preventing the root mechanisms of cancer development.

It is also important to investigate how the experience of genetic testing for cancer susceptibility is gendered. In the case of BRCA1 & 2, this would mean more closely examining the role of men in families with a cancer history. It would be interesting to explore how gender interacts with the cultural influences surrounding the perceived benefits and disadvantages to genetic testing. Gender could also alter the way risk is constructed and the psychological consequences of genetic testing, in both a family and an individual context.

Finally, the importance of family experience in creating an embodied knowledge of cancer risk and as a basis from which to challenge, reinforce, or negotiate biomedical information needs to be more clearly recognized. Genetic counsellors need to be aware how such processes of knowledge creation are affecting the final information that counselling clients are taking home with them. Such processes will probably also have an important role to play in understanding how individuals perceive risk under other circumstances. Further study in this area could outline more precisely the mechanisms by which information is transformed into the embodied knowledge that encompasses action.

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# Appendices

## Appendix A: Interview Protocol

Background – Self Identification

1. Could you give me a short thumbnail sketch of your life, just to highlight some of the things you think are or were important, such as your childhood, education, work, or your family?

Background – genetic testing

2. Would you tell me how you got involved in the genetic counselling/testing process?
3. How and why did you arrange a genetic counselling session?
4. What is the history of cancer in your family?
5. When and how did you learn about the possibility of becoming genetically tested for BRCA1?
6. (T) Who or what was important in influencing how you made your decision of whether or not to be tested for BRCA1?
7. (T) Did you find the decision difficult to make?
8. (T) What did you think about the process of being tested/the period of testing?
9. What sort of effects did the outcome of the decision to be tested / inability to be tested have on your family?
10. What do you think of genetic testing for genes like BRCA1/2? What are the positives and negatives of testing?

Genetic Counselling

11. What information did you want to get from your genetic counselling session(s)?
12. How did this compare with the information given in the session(s)?
13. Would you have liked anything to be different in your genetic counselling session(s)?
14. What did you find most helpful/interesting about your genetic counselling session(s)?

Genetics

15. What do you understand about genetics?
16. Can you explain how a susceptibility for breast cancer is passed on in families?

Risk

17. (W) How did you see your risk of developing breast &/or ovarian cancer prior to counselling session?
18. (W) How do you see your risk of developing breast &/or ovarian cancer now?
19. Do you think that it is important for men to be tested for BRCA1/2? (Why/Why not?)

Prevention/Maintenance of Health

20. Do you think cancer is something that you can actively prevent? (Why?)
21. What do you think about the effect of things like diet, vitamins and other similar things on the development of cancer?
22. How important do you think breast self exams, breast examination, and mammography?
Checklist: modified diets, nutritional supplements, pharmaceutical agents, prophylactic mastectomy and oophorectomy, mammography, breast self-examination, other alternative methods of prevention, herbal treatments, etc.
23. (W) Do you make use of any of these? Why or why not?
24. (W) How does participating in these activities make you feel?

Open-ended Closing Question

25. Before we finish is there anything you would like to add or to emphasize, or would you have any advice for a woman in a similar situation?

## Appendix B: Letters of Consent

Letter of Consent used on Vancouver Island

By signing this letter, you give your consent to participate in the research study "Genetic Testing for Breast Cancer: Risk Perception and Motivation for Prevention." The research project is studying genetic testing for BRCA1, including attitudes towards prevention of breast and ovarian cancer and an individual's understanding of risk. You will be asked in an interview about your experience with genetic testing and counselling as well as what you think your risk of developing breast or ovarian cancer is and ways of preventing breast and ovarian cancer. Your interviewer for this project will be Christina Holmes, a Masters student at the University of Victoria, who will be supervised by Dr. Peter Stephenson (University of Victoria) and Dr. MacLeod (Medical Genetics Department, Victoria General Hospital). The purpose of the research is to improve communication about genetic testing and about preventive strategies to avoid breast cancer, as well as to increase the understanding of how genetic testing affects people's lives. The results will be reported to the Victoria General Hospital Medical Genetics department and may be published in a scholarly journal.

Your participation in the interview will require approximately one hour. With your permission, the interview will be tape recorded and then transcribed into written form. The audio tapes will be destroyed immediately after they have been typed out. Your name, or the names of any individuals mentioned by you, will not appear on any written documentation, as real names will be replaced with code names, only known by Christina Holmes, to ensure confidentiality. Only Christina Holmes and, if needed, her supervisor and graduate committee will have access to the written version of the interview. The written transcripts of the interviews will be destroyed after the research project is completed.

Your participation is completely voluntary and you have the right to stop the interview at any time, without explanation, and ask for any records of the part of the interview already completed to be destroyed. You also have the right to refuse to answer any questions.

Signature of participant: Date:

Please sign below if you give your permission for written parts of the interview to be quoted directly, provided that no identifying features are used (name, age, occupation, etc.)

Signature of participant: Date:

Researcher: Christina Holmes
Phone: (250) 598-1229

Supervisor: Dr. Peter Stephenson
Phone: 721-7351

Letter of Consent used on the Lower Mainland for those who had undergone genetic testing.

## PATIENT INFORMATION AND CONSENT FORM

| | |
|---|---|
| **Name of Study:** | Genetic Testing and Breast Cancer:<br>Risk Perception and Motivation for Prevention |
| **Institute:** | BC Cancer Agency<br>Victoria General Hospital |
| **Principal Investigator:** | Karen Panabaker (B.Sc., M.Sc., M.Sc.) |
| **Co-Investigators:** | Christina Holmes (B.A.), Dr. Peter Stephenson (B.A., M.A., PhD) |

By signing this letter, you give your consent to participate in the research study "Genetic Testing for Breast Cancer: Risk Perception and Motivation for Prevention." Your interviewer for this project will be Christina Holmes, a Masters student at the University of Victoria, who will use this project for a Master's thesis. She will be supervised by Karen Panabaker (Genetic Counsellor, BC Cancer Agency) and Dr. Peter Stephenson (Professor and Chair, University of Victoria).

The research project is studying perceptions about genetic counselling held by women with a high family history of breast and ovarian cancer. Included are both women who have and have not been tested for mutations in the first gene (BRCA1) to be linked to these cancers. Topics investigated include attitudes towards prevention of breast and ovarian cancer and an individual's understanding of risk. You will be asked in an interview about your experience with genetic testing and counselling as well as what you think your risk of developing breast or ovarian cancer is and ways of preventing breast and ovarian cancer. The purpose of the research is to improve communication about genetic testing and about preventive strategies to avoid breast cancer, as well as to increase the understanding of how genetic testing affects people's lives.

The results will be reported to the Hereditary Cancer Program of the BC Cancer Agency, the Medical Genetics department of Victoria General Hospital, the BC Health Research Foundation, the Sara Spencer Foundation and may be published in a scholarly journal.

Your participation in the interview will require approximately one hour. The interview will be tape recorded and then transcribed into written form. The audio tapes will be destroyed immediately after they have been typed out. Your name, or the names of any individuals mentioned by you, will not appear on any written documentation, as real names will be replaced with code names, only known by Christina Holmes, to ensure confidentiality. Only Christina Holmes and, if needed, her supervisor and graduate committee will have access to the written version of the interview. The typed transcripts will be kept in a locked filing cabinet and computer files will only be accessible by password. The transcripts of the interviews will be destroyed after the research project is completed.

Your participation is completely voluntary and you have the right to stop the interview at any time, without explanation, and ask for any records of the interview to be destroyed. Refusal to participate or withdrawal from this study will not jeopardize any further medical care. You also have the right to refuse to answer any questions. Patient's rights are protected by the BC Privacy and Protection Act. This means that the researchers are legally obligated to not divulge your name to third parties.

If you have any questions concerning the above, please do not hesitate to contact either the interviewer, Christina Holmes at (250) 598-1229 or one of her supervisors. If you have any concerns about your rights or treatment as research participants, you may contact Dr. Richard Spratley, Director of Research Services at the University of British Columbia, at (604) 822-8598. You will receive a copy of the consent form for your own records.

This study is sponsored by the University of Victoria Sara Spencer Foundation and the British Columbia Health Research Foundation.

Signature of participant: Date:

________________________________________ ____________

Please sign below if you give your permission for written parts of the interview to be quoted directly, provided that no identifying features are used (name, age, occupation, etc.)

Signature of participant: Date:

________________________________________ ____________

Signature of investigator: Date:

________________________________________ ____________

Principal investigator: Karen Panabaker
Phone: (604) 877-6000 (2118)

Co-investigator and interviewer: Christina Holmes
Phone: (250) 598-1229 (If calling long distance, please call collect.)

Co-investigator and supervisor: Dr. Peter Stephenson
**Phone: (250) 721-7351**

Letter of Consent used on the Lower Mainland for those who had been ineligible for genetic testing.

## PATIENT INFORMATION AND CONSENT FORM

**Name of Study:** Genetic Testing and Breast Cancer:
Risk Perception and Motivation for Prevention

**Institute:** BC Cancer Agency
Victoria General Hospital

**Principal Investigator:** Karen Panabaker (B.Sc., M.Sc., M.Sc.)
**Co-Investigators:** Christina Holmes (B.A.), Dr. Peter Stephenson (B.A., M.A., PhD)

By signing this letter, you give your consent to participate in the research study "Genetic Testing for Breast Cancer: Risk Perception and Motivation for Prevention." Your interviewer for this project will be Christina Holmes, a Masters student at the University of Victoria, who will use this project for a Master's thesis. She will be supervised by Karen Panabaker (Genetic Counsellor, BC Cancer Agency) and Dr. Peter Stephenson (Professor and Chair, University of Victoria).

The research project is studying perceptions about genetic counselling held by women with a high family history of breast and ovarian cancer. Included are both women who have and have not been tested for mutations in the first gene (BRCA1) linked to these cancers. Topics investigated include attitudes towards prevention of breast and ovarian cancer and an individual's understanding of risk. You will be asked in an interview about your experience with genetic counselling as well as what you think your risk of developing breast or ovarian cancer is and ways of preventing breast and ovarian cancer. The purpose of the research is to improve genetic counselling communication about preventive strategies to avoid breast cancer, as well as to increase the understanding of how genetic counselling and testing affects people's lives.

The results will be reported to the Hereditary Cancer Program of the BC Cancer Agency, the Medical Genetics department of Victoria General Hospital, the BC Health Research Foundation, the Sara Spencer Foundation and may be published in a scholarly journal.

Your participation in the interview will require approximately one hour. The interview will be tape recorded and then transcribed into written form. The audio tapes will be destroyed immediately after they have been typed out. Your name, or the names of any individuals mentioned by you, will not appear on any written documentation, as real names will be replaced with code names, only known by Christina Holmes, to ensure confidentiality. Only Christina Holmes and, if needed, her supervisor and graduate committee will have access to the written version of the interview. The typed transcripts will be kept in a locked filing cabinet and computer files will only be accessible by password. The transcripts of the interviews will be destroyed after the research project is completed.

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If you have any questions concerning the above, please do not hesitate to contact either the interviewer, Christina Holmes at (250) 598-1229 or one of her supervisors. If you have any concerns about your rights or treatment as research participants, you may contact Dr. Richard Spratley, Director of Research Services at the University of British Columbia, at (604) 822-8598. You will receive a copy of the consent form for your own records.

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Signature of participant: Date:

_______________________________________ ____________

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Signature of participant: Date:

_______________________________________ ____________

Signature of investigator: Date:

_______________________________________ ____________

Principal investigator: Karen Panabaker
Phone: (604) 877-6000 (2118)

Co-investigator & interviewer: Christina Holmes
Phone: (250) 598-1229 (If calling long distance, please call collect.)

Co-investigator and supervisor: Dr. Peter Stephenson
**Phone: (250) 721-7351**

# VITA

Surname: Holmes                Given Names: Christina Patrice

Place of Birth: Bangkok, Thailand

Education Institutions Attended:

| | |
|---|---|
| University of Victoria | 1997-2000 |
| University of Victoria | 1991-1996 |

Degrees Awarded:

| | | |
|---|---|---|
| B.A. | University of Victoria | 1996 |

Honours and Awards:

| | |
|---|---|
| BC Health Research Foundation Studentship | 1998-1999 |
| Sara Spencer Award for Applied Research | 1998-1999 |
| University of Victoria Scholarship | 1998-1999 |
| University of Victoria Teaching Assistant Scholarship | 1997-1998 |

Publications:

n.d. Stephenson, Peter H. and Christina Holmes. "The Elders Listening Project: Elder Friendly Hospital Initiative of the Capital Health Region: Final Report" Unpublished report for the Capital Health Region.

2000 *Review of* Feminist Fields: Ethnographic Insights. Cultural Reflections 2:70-71.

2000 *Review of* Why We Buy: The Science of Shopping. Cultural Reflections 2:71-72

1998 Chinese Immigrants in Canada: Institutionalized Racism and Organized Protest. Cultural Reflections 1:15-20.

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Title of Thesis:

"You're Armed, I Think You're Better Armed": Women's Opinions of Genetic Counselling and Testing for Hereditary Breast and Ovarian Cancer Susceptibility (BRCA1).

Auth[redacted]

Christina Patrice Holmes
August 15, 2000