EXPERIENTIAL KNOWLEDGE, MORAL AGENCY AND GENETIC TESTING FOR HEREDITARY BREAST/OVARIAN CANCER

by

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This study examined the influence of genetic testing for hereditary breast/ovarian cancer on individuals' understandings of self and moral agency. Using an ethnographic design, the investigator conducted in-depth interviews with 53 individuals (45 female, eight male) from families at high-risk for hereditary breast/ovarian cancer. Working closely with genetic counsellors and geneticists at the Hereditary Cancer Program (HCP), BC Cancer Agency, she also undertook approximately 50 hours of fieldwork as an observer in genetic counselling sessions. In addition, she regularly attended clinical review and steering meetings of the HCP. The research focused primarily on the accounts of at-risk individuals who underwent testing and those who were eligible but declined testing.

The impact of genetic information was examined through three interrelated aspects of self: the embodied, relational and social self. Most participants linked their positive results to becoming more aware of their embodied selves. The information was generally viewed as enabling; it allowed participants to take measures (surveillance or prophylactic surgery) to confront the disease. However, for a small minority of women knowledge about their genetic risk had a profound and limiting effect on their agency. Rather than giving them a sense of control, they saw little opportunity to fight the disease. They were overcome by thoughts of their embodied risk and a dire future from which they could not escape. A few others were thrust into a state of uncertainty. These participants did not view themselves as risk-free, yet neither did they perceive themselves as unhealthy. While worrisome at times, knowledge of their mutation status became part of their awareness, part of their routine lives and ultimately part of who they were.
Genetic testing is enacted within a discursive practice (medical, ethical and legal) that gives primacy to individualistic models of autonomy, rational decision-making and choice. Yet, the research showed that a relational concept of autonomy provides a better framework for understanding some of the complexities raised by genetic testing for hereditary cancer. Participants' decisions to seek testing reflected practical concerns about their health, but the self in relation to others was also instrumental in making these decisions. Some women believed testing could give their daughters, sisters and other female relatives information that would be useful for them. Others, referring to their own experiences with breast/ovarian cancer, hoped that genetic information would allow family members greater control over the disease. Many participants also wished to be tested in order to provide information that might benefit medical research and society more broadly. Although some participants spoke of individual choice, the language of responsibility coexisted and often prevailed over that of individual rights. Responsibility to others was not seen as an abstract obligation, but as a complex expression of self-governance through which people expressed their sense of moral agency.

The investigator concluded by discussing the clinical import of the research findings, especially with respect to genetic counselling practices and informed consent. She called for more ethnographic work examining the impact of genetic information on adolescents and young adults. Lastly, she emphasized the value of integrating empirical studies with ethical assessment of new medical technologies in order to build a bioethics that is more sensitive to the ethical concerns which structure people's everyday lives.
## TABLE OF CONTENTS

Abstract ii  
Table of Contents iv  
List of Tables viii  
Acknowledgements ix  

### CHAPTER ONE: SITUATING THE STUDY

- Introduction 1  
- Background to the Problem 2  
  - Bioethics 5  
- The Research Problem: Purpose and research questions 7  
- Significance of Research 9  
- Situating the Research 10  
  - Researcher as Self (ves) 11  
- Organization of Thesis 13  

### CHAPTER TWO: EXPLORING THE SCIENTIFIC AND CLINICAL LANDSCAPE

- Introduction 15  
- Breast/Ovarian Cancer: A hereditary cancer syndrome 17  
  - Benefits and Limitations 22  
  - Prevention Strategies 25  
- Psychosocial Implications of Testing 27  
  - Attitudes towards testing 28  
  - Psychological distress 31  
  - Limitations of psychological studies 33  
- Qualitative Studies 36  
- Current Testing Practices 40  
  - Clinical criteria: Who is eligible for testing? 40  
  - The B.C. experience 41  
  - The political landscape 44  
- Summary 46  

### CHAPTER THREE: SURVEYING THE ETHICAL TERRAIN

- Introduction 48  
- Mainstream approaches to bioethics 49  
  - Principilism 49  
  - Casuistry 52  
  - Virtue based theory 54  
  - Care Ethics 55  

CHAPTER FOUR: CONSTRUCTING MEANINGS

Introduction

Ethnography: An overview
  Feminist Contributions

Building the ethnographic terrain

Research design
  Sampling and recruitment
  Participant observation
  Interviews
  Analysis
  Trustworthiness and validity

Reflexivity
  Ethnographic tools revisited
  Telling and listening
  Dialogical understandings
  Listening and telling

Summary

CHAPTER FIVE: NARRATIVES IN CONTEXT

Introduction

Beginnings

Empathetic knowledge
  Tangible knowing
  Other ways of knowing
  Recent knowing
  Distant knowing
  Accidental knowing: learning by chance

Embodied knowledge

From cancer knowledge to risk identity

Summary

CHAPTER SIX: MAKING CHOICES

Introduction

Embodied self
  Knowledge is power

Relational self
<table>
<thead>
<tr>
<th>Chapter Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Benefiting the larger family</td>
<td>171</td>
</tr>
<tr>
<td>Responsibility and coercion</td>
<td>176</td>
</tr>
<tr>
<td><strong>Social self</strong></td>
<td>180</td>
</tr>
<tr>
<td>Reasons for <em>not</em> testing</td>
<td>182</td>
</tr>
<tr>
<td><strong>Embodied self</strong></td>
<td>183</td>
</tr>
<tr>
<td>Treatment options</td>
<td>186</td>
</tr>
<tr>
<td><strong>Relational self</strong></td>
<td>189</td>
</tr>
<tr>
<td>Social self</td>
<td>192</td>
</tr>
<tr>
<td><strong>Summary</strong></td>
<td>194</td>
</tr>
</tbody>
</table>

**CHAPTER SEVEN: GENETIC TESTING AND UNDERSTANDINGS OF SELF**

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>198</td>
</tr>
<tr>
<td><strong>Embodied self</strong></td>
<td>200</td>
</tr>
<tr>
<td>Aware self</td>
<td>202</td>
</tr>
<tr>
<td>Safe self</td>
<td>204</td>
</tr>
<tr>
<td>Negative results</td>
<td>209</td>
</tr>
<tr>
<td>Risky self</td>
<td>213</td>
</tr>
<tr>
<td>Uncertain self</td>
<td>216</td>
</tr>
<tr>
<td><strong>Relational self</strong></td>
<td>220</td>
</tr>
<tr>
<td>Concern for others</td>
<td>220</td>
</tr>
<tr>
<td>Disclosure of genetic information</td>
<td>229</td>
</tr>
<tr>
<td><strong>Social self</strong></td>
<td>237</td>
</tr>
<tr>
<td>Age-related concerns</td>
<td>241</td>
</tr>
<tr>
<td>Young adult women</td>
<td>242</td>
</tr>
<tr>
<td><strong>Summary</strong></td>
<td>250</td>
</tr>
</tbody>
</table>

**CHAPTER EIGHT: ATTENDING TO BROADER SOCIAL DISCOURSES**

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>255</td>
</tr>
<tr>
<td><strong>The ideology of genetic determinism</strong></td>
<td>257</td>
</tr>
<tr>
<td><strong>Ideologies of breast cancer: the discourse of survivorship</strong></td>
<td>269</td>
</tr>
<tr>
<td><strong>The ideology of choice; the context of responsibility</strong></td>
<td>276</td>
</tr>
<tr>
<td><strong>Relational selves</strong></td>
<td>285</td>
</tr>
<tr>
<td>Relational selves and experiential knowledge</td>
<td>286</td>
</tr>
<tr>
<td>Relational selves and moral identity</td>
<td>288</td>
</tr>
<tr>
<td>Relational selves: biological relatedness and social identity</td>
<td>290</td>
</tr>
<tr>
<td>Relational selves and responsibility</td>
<td>293</td>
</tr>
<tr>
<td><strong>Summary</strong></td>
<td>296</td>
</tr>
</tbody>
</table>

**CHAPTER NINE: TOWARDS FURTHER UNDERSTANDING OF GENETIC TECHNOLOGIES**

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>299</td>
</tr>
<tr>
<td>Summary of findings</td>
<td>300</td>
</tr>
<tr>
<td><strong>Methodological reflections</strong></td>
<td>303</td>
</tr>
<tr>
<td><strong>Clinical implications</strong></td>
<td>307</td>
</tr>
</tbody>
</table>
# LIST OF TABLES

<table>
<thead>
<tr>
<th>Table Number</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Recruitment and Participation Rate</td>
<td>96</td>
</tr>
<tr>
<td>2</td>
<td>Genetic Testing for BRCA 1/2 Mutations: Participant Categories</td>
<td>99</td>
</tr>
<tr>
<td>3</td>
<td>Genetic Test Results for BRCA 1/2 Mutations</td>
<td>99</td>
</tr>
<tr>
<td>4</td>
<td>Demographic Profile of Participants</td>
<td>100</td>
</tr>
<tr>
<td>5</td>
<td>Genetic Testing for BRCA 1/2 Mutations: Participant Profile</td>
<td>158</td>
</tr>
<tr>
<td>6</td>
<td>Genetic Test Results: Breakdown by Cancer Status</td>
<td>201</td>
</tr>
</tbody>
</table>
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CHAPTER 1:

Situating the Study

The early detection of women at high risk provides a promising approach for reducing the high incidence and mortality associated with breast and ovarian cancer. These women, once identified can be targeted for more aggressive prevention programs. The isolation of the BRCA1 genes now allows us to proceed with the identification and understanding. (L. Cannon-Albright & M. Skolnick, 1996)

The potentially sick, potentially vulnerable and potentially stigmatized are not an esoteric group of people. They are all of us waiting for our harmful genes to be identified. (R. Kenen, 1994)

Although accumulating evidence indicates that mutations in the BRCA1 and BRCA2 genes are only a small part of the puzzle of inherited risk, the lessons to be derived from BRCA1 and BRCA2 research are profound. Genetics has left the era of monogenic disease and entered the era of complex, gene-environment interactions—in short, genetics has entered the world of common diseases. The research challenges involved in exploring this world are daunting, but they represent the next important step in addressing the problem of cancer. (W. Burke, N. Press and L. Pinsky, 1999)

Introduction

The quotations above reveal the complex, and often contradictory, reactions to genetic testing for hereditary breast/ovarian cancer. Hailed by some as a major medical breakthrough, advocates purport that information gained from genetic testing will facilitate early intervention, allowing women to take measures that may ultimately save their lives. Others view genetic testing as far more sinister, promising to usher in a new era of discrimination and to control people in untoward ways. And others still, describe genetic technology as in its infancy. They argue that far more research is needed to determine how genetics interacts with other factors in causing both hereditary and non-hereditary cancers. Within this polemic maelstrom, however, are women and men who actually seek these tests. How do their experiences accord with these enthusiastic or cautionary tales? Namely, what impact does genetic information for hereditary breast/ovarian cancer have on people’s lives?
This study aims to contribute to the understanding of the complex moral and social issues generated by genetic testing for hereditary breast/ovarian cancer. The ethics and social science literature has posed difficult questions about privacy, confidentiality of information and genetic discrimination if a mutation is found (Knoppers and Godard 1998; Lemmens and Bahamin 1998; Sherwin and Simpson 1999; Sommerville and English 1999; Weijer 2000; Burgess 2001; Henderson 2001). Yet, it is important to balance theoretical concerns with people’s subjective experiences with genetic testing. Evaluating the moral and social effects of genetic testing requires that we go beyond abstract discussion to examine the life circumstances in which people make their decisions and live with genetic information. It directs us to attend to the specific histories, experiences, values, commitments and meanings that women bring to genetic testing and the impact this information has on their lives. It gives rise to questions such as: Does genetic knowledge change the way people think about themselves or relate to others? Does it expand, enhance or restrict the control they have in their lives? At the same time, it is important to ask in what ways do social, institutional and political structures shape public understanding and engagement with this kind of technology? By profiling the subjective experiences of those who have undergone genetic testing for hereditary breast/ovarian, this dissertation aims to address these questions.

Background to the problem

Inherited predisposition to cancer has become an increasingly important part of the practice of clinical genetics. Epidemiological studies have indicated that there is a genetic component to cancer and that 5% to 10% of women who develop breast/ovarian cancer do so because of an inherited predisposition (Newman, Millikan et al. 1988; Clauss, Risch et al.)
Two genes, BRCA1 and BRCA2, associated with hereditary breast/ovarian cancer have been identified (Miki, Swenson et al. 1994; Wooster, Neuhausen et al. 1994; Wooster 1995). The sequencing of these genes has led to a blood test that can identify carriers of mutated genes. Thus genetic testing creates the unique situation in which individuals may learn in advance whether they are at increased risk for developing hereditary breast/ovarian cancer.

Although there is no effective prevention for breast/ovarian cancer, it is widely assumed informing persons about their genetic risk is beneficial. Genetic information, it is posited, may lead to reduced morbidity and mortality (Burke 1997; Muto 1997; Olopade 1997). Researchers suggest that genetic testing will be of benefit to persons concerned, as well as society, because it will permit more rational targeting and use of cancer surveillance programs. Persons found to be negative will be relieved of anxiety about the threat of disease in themselves and/or their children, and those found to be positive will be empowered to plan their lives accordingly.

From this perspective, genetic testing is seen primarily as a technology that will assist individual decision-making. It is based on a medical model that views the individual as rational, independent and autonomous. Although theorists debate the exact definition of autonomy, respect for the principle “is usually interpreted as acknowledging and protecting competent patient’s authority to respect or refuse whatever specific treatments the health care providers they consult find it appropriate to offer them” (Sherwin, 1998; p. 21). It is understood as the individual’s right to direct their health care based on their own values and

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1 BRCA1 and BRCA2 genetic mutations predispose to both breast and ovarian cancer. In some families, there is an aggregation of breast cancer, in others ovarian cancer and still in others, both. Because most participants in this study came from families with a history of breast cancer, for the purposes of this thesis, I refer mainly to hereditary breast cancer.
notions of welfare. Seen from this vantage point, informing persons about the benefits and harms of genetic testing not only protects their rights as autonomous decision-makers, but also empowers them to exercise personal control over their lives. Indeed, genetic testing may be seen as a technology that can inform medical and personal life decisions. It offers information that, according to a European report on ethical and philosophical issues of genetic screening, “will facilitate autonomy” (Chadwick & Levitt, 1996: 67).

Yet, recent publications stress the importance of social context in understanding choices, behavior and ethical concerns raised by genetic testing (Burke 1997; Muto 1997; Olopade 1997; Lippman 1998; Cox 1999; Cox and McKellin, 1999; Sherwin and Simpson 1999; Burgess 2001; Henderson 2001). Indeed, the decision to undergo testing is not made in isolation, but influenced by a complex mix of familial, cultural and social life experiences. This view points to the significance of recognizing values, interests, responsibilities and relationships in influencing choices made with respect to genetic testing. It also brings to bear feminist and communitarian concepts of autonomy, in which relationships are considered central in constituting the self (Taylor 1989; Held 1993; Bowden 1997; Tong 1997). As Sherwin so cogently writes: “Much of who we are and value is rooted in our relationships with others” (1998, p. 34). Clearly, a decision to have genetic testing is both shaped by and woven into other life experiences, circumstances and commitments. The latter, in turn, will impact how genetic information is interpreted and acted upon. A broader ethical analysis also requires that we look at specific decisions within the context that influences, and sometimes constrains, those decisions. Currently, very little work has been done in these areas.
Bioethics

The purpose of my doctoral research is to examine some of the complex social and moral issues raised by genetic testing for hereditary breast/ovarian cancer. I wish to explore the impact of genetic information on people’s everyday lives and their understandings of self and agency. I also wish to explore whether the moral issues raised by users of the technology may contribute to a broader ethical framework from which to assess this and other genetic technologies. Thus, what I am describing is both research on an issue that has ethical implications, as well as research that may expand the scope of ethical discussion. This latter goal requires some reflection on the shortcomings of traditional bioethics.²

To date, bioethics has relied heavily on the language of principles and rights, as well as social good in assessing the morality of actions or policies. Although concerned with protection of the patient, bioethics tends to approach problems from the physician’s vantage point (Hoffmaster 1992; Sherwin 1992; Wolf 1996b; Hoffmaster 2001). Indeed, ethics work in genetics has emphasized clinical measures of effect, clinicians’ responsibilities for the effects of tests or information, and patient autonomy for decisions made within genetic counselling and regarding health care (Mastromauro, Meyers et al. 1987; Wiggins, Whyte et al. 1992; Babul, Adam et al. 1993; Meyers 1997). These studies have been criticized for their over-generalization about attitudes towards testing and their emphasis on clinical service approaches (Wiggins, Whyte et al. 1992; Burgess and Hayden 1996). They provide little basis for understanding the moral experiences of individuals and how genetic information is assimilated into their lives. They also fail to recognize patients’ concerns about family relations in their analysis of moral issues (Burgess, 2001).

² In adherence with Susan Wolf’s (1996b) definition, I take bioethics to mean the study and formulation of ethics of health care and the biological sciences
Marshall and Koenig (1996) observe that the application of philosophical principles to the resolution of ethical dilemmas “complements the Cartesian duality associated with the biomedical model of disease” (p.12). Just as scientific medicine perceives itself as a search for knowledge free of social values, bioethics aspires towards “dispassionate objectivity” (Elliott 1999: xxiii). Each is embedded in the nature/culture oppositions of Western thought, where nature is considered a given and culture as something designed to master nature through rationality, science and technology (Lock 2001). Both strive for impartiality and general truth claims (Gordon 1988; Rapp 1993). Indeed, grounded in analytic philosophy, biomedical ethics deals largely with the application of well-defined moral theories and rules to problems that arise in health care (Ten Have and Lelie 1998). Most commonly championed in western health care are the four principles – respect for autonomy, beneficence, non-maleficence and justice (Marshall and Koenig 1996). By providing ‘rational’ standards by which to judge medical problems, bioethics aims to be normative, replacing “what is” with “what ought to be.” Bonded to abstractions of reason and theory, social context has been largely ignored (Hoffmaster 1992; Hoffmaster 2001).^3

In the last decade, however, a number of bioethicists and social scientists have expressed dissatisfaction with this abstract approach (Gordon 1988; Hoffmaster 1990; Hoffmaster 1992; Marshall 1992; Conrad 1994; Marshall and Koenig 1996; Nelson 2000; Zussman 2000; Hoffmaster 2001; Burgess in preparation). With growing recognition that medical morality is embedded in a social and cultural context, bioethics scholars have emphasized the need for a theoretical model that emphasizes social practices rather than

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^3 As Ten Have and Lelie (1998) remark, up until recently this inattention to social context has not been considered a failure but “a duty, necessary to accomplish good ethical practice, since moral discourse can only be normative and prescriptive as long it has a decontextualized and abstract approach to health care practices” (p. 267).
abstract theories. As Hoffmaster (1992) states: "What is needed is a different brand of moral theory, one that is more closely allied with and faithful to real-life phenomena. Ethnography has a vital role to play in developing a more empirically grounded theory of morality" (p. 1425) Indeed, ethnography as Conrad (1994) writes, can help shift "the bioethical gaze" from the individual to an interactive process that occurs within a social context.

Social scientists have recently begun to employ ethnographic techniques to examine the moral dimensions of biomedicine. Among other things, ethnography has been used to explore the ethics of neonatal and adult intensive care (Jennings 1990; Zussman 1992; Anspach 1993), organ transplantation (Fox and Swazey 1992; Fox 1996; Lock 2001), genetic counselling (Bosk 1992), prenatal diagnosis (Rothman 1986; Rapp 1999), informed consent (Kass, Sugarman et al. 1996) and practices of disclosure (Gordon and Paci 1997). Geller and colleagues have also employed ethnographic techniques to explore attitudes towards genetic testing for hereditary breast/ovarian cancer and related issues of informed consent (Geller, Bernhardt et al. 1995; Bernhardt, Geller et al. 1997; Geller, Strauss et al. 1997; Gordon and Paci 1997; Geller 2000). Similarly, I selected ethnography as the most appropriate method for this study because it provided me the opportunity to construct a contextualized understanding of moral issues raised by genetic testing for hereditary breast/ovarian cancer. I also employed ethnography in hopes of connecting theoretical development in bioethics with the messiness of everyday life.

**The research problem: purpose and research questions**

As previously stated, genetic testing creates the unique situation in which individuals may learn in advance whether they are at increased risk for developing hereditary breast/ovarian cancer. Yet, to my knowledge no studies have attempted to explore the
influence of genetic information on people’s concepts of self, personhood or expressions of their moral agency. This study endeavors to address this gap. In conducting an empirical study, my research is directed toward gaining an understanding of genetic testing as lived. The purpose is to provide rich contextual detail regarding the meanings, motives, concerns and values people bring to genetic testing. My aim is to describe the moral issues raised by the availability and use of this technology and how people contend with these issues. Through participants’ descriptions, I hope to gain insight into the meanings people give to genetic information and how they assimilate this information into their everyday lives.

The questions shaping this study are both descriptive and interpretive, and can be categorized into two broad areas: What brings people to genetic testing for breast/ovarian cancer? Secondly, what is the significance of genetic testing on people’s everyday lives? From these two broad categories other research questions emerge: What does it mean for women to be identified and to identify themselves or other family members at risk for hereditary breast cancer? Does genetic information influence how individuals think about themselves, relate to others or perceive responsibilities to family members as well as to the community at large? Does it impact those things that people care most deeply about and take responsibility for?

This study will start from the perspectives of women/men who are eligible for and/or who have undergone genetic testing for hereditary cancer. It will take into account people’s experiences living with familial cancer as well as the larger social context in which genetic

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4Given the morass of social, psychological and philosophical literature on the ‘self’ and identity, a note on terminology is needed here. For the purposes of this study, I use the ‘self’ to refer to the inner, personal and private, the subjective experience of self (Estroff, 1993). I refer to identity, on the other hand, when discussing the public, social, or more formal role-based aspects of self (Estroff, 1993; Whittaker, 1992). At the same time, I do not look at either self or identity as something fixed but rather fluid and diverse. Each, as Rose (1993) points out, is located with particular matrices of historical, social and class positions.
technology is utilized. This context is not a neutral zone, but one in which genetics, and the Human Genome Project more generally, has garnered considerable attention from health care professionals, social scientists as well as the lay press. Breast cancer has also become highly politicized and is the focus of substantial research and media attention. Ethnography is the most appropriate methodology for my research in that it will enable me to critically examine the larger social context of health care, breast cancer and genetic testing in relation to the experiences of those using the technology. My goal is to detail the diversity, ambiguity and contradictions I find, while at the same time, trying to characterize commonalities generated by experiences with this particular technology.

**Significance of research**

This research aims to provide new insight into the understanding of the moral and social impact of genetic testing for hereditary breast/ovarian cancer. This is an important area to explore for several reasons. First, increased understanding of the impact of genetic testing will contribute to a more accurate assessment of the ethical and social implications of this technology. As Gillet (2001) observed, because of the abstract and prescriptive manner in which ethical issues are cast, it is possible to lose sight of the things that really matter to people. Secondly, the understanding and articulation of participants’ moral and social experiences lays the groundwork for evaluating current policy and clinical practice regarding genetic testing for hereditary breast/ovarian cancer. I anticipate that the results from this study can be used to identify the kinds of interventions needed to shift the allocation of health resources towards priorities identified by users of this technology, or to provide some suggestions on how best to support people with their concerns. And lastly, empirical work
offers to shed further insight into the nature of moral agency and thus contribute to ethical reflection and theoretical development in bioethics.

Before I begin, however, a preliminary note about terminology might be helpful. Scholars frequently use the terms morality and ethics interchangeably. In order to be clear, I take as my starting point a characterization of morality offered by Margaret Urban Walker (1998). Morality, she writes, “tells us something deep and central about how to live” (p. 3). It refers to those values that shape the way we see ourselves, and how we ought to live our lives. Embedded in, and fashioned by, particular relationships and social settings, morality is comprised of shared understandings that inform our beliefs, motivations and choices. It is central to how we understand concepts such as trust, kindness, respect, obligation, blame, accountability and responsibility. Morality, according to Walker, converges around notions of identity, relationships and values, as well as people’s understandings of their own and other’s responsibilities. It is born in action and thought, and intertwines with social practices. Ethics, on the other hand, encompasses the reflective, systematic and normative study of morality (Sherwin 1992; Walker 1998; Sulmasy and Sugarman 2001). It is concerned “with value questions about human conduct” (Sherwin, 1992: 35). Taking my lead from Walker then, my work will attempt to describe how genetic testing impacts people’s constructions of their moral selves. I also hope to contribute to the ethical implications of this technology.

Situating the research

Postmodern strategies recognize the reflective nature of research. As many authors have argued, the neutrality of the observer can no longer be held in either quantitative or qualitative research (Oakley 1981; Hammersley and Atkinson 1983; Keller 1985; Harding 1986; Haraway 1988; Anderson and Jack 1991; Harding 1991). As Oakley (1981) remarks:
"The mythology of the “hygienic” research with its accompanying mystification of the researcher and the researched as objective instruments of data production must be replaced by the recognition that personal involvement is more than a dangerous bias – it is the condition under which people come to know each other and to admit others into their lives.” I concur that my approach to research is mediated through my own understandings and experiences. It is thus important that I acknowledge at least some of the biography that I bring to that research. Here, I present a brief description of myself as researcher and how I became interested in this area of scholarship.

Researcher as self(ves)

This thesis actually had its origin some 12 years before I started my doctorate program at UBC. My academic interests began in Behavioral Ecology (Master’s of Zoology) and from there I pursued a career in science and medical journalism. This took me from Toronto to Long Beach, CA. and lastly to San Francisco where I held the position of ‘News Editor’ for a medical magazine. The job entailed not only writing and editing, but traveling extensively to conferences throughout the U.S., Canada and Europe as I reported on emerging medical developments. Initially, I found the work exciting. I greatly enjoyed learning about new medical breakthroughs and the challenge of communicating this information to diverse audiences. However, as time went on, I became somewhat uncomfortable with the medical focus I had adopted. Although I could not articulate it at the time, I grew increasingly dissatisfied with a discipline that viewed health and illness in purely biological terms. I found myself questioning some of the basic fundamentals of medicine, including what counts as disease? Who gets to name it? Who is healthy and who is not? How does the naming of illness affect people’s lives?
Following the birth of our first child, my husband and I decided to return to Canada in 1989. I maintained a working relationship with the same medical magazine for several more years as a contributing editor. I also organized and served as chief editor on several independent publications for them. I gradually tired of the isolation, however, and in September 1994 made the decision to pursue magisterial work in science education at Simon Fraser University. Nearing the end of my coursework, I enrolled in a seminar course on qualitative methodology. As someone who had adhered to “positivist” research, I was intrigued to learn what this methodology was all about. I had also heard that this particular course (taught by Dr. Celia Haig-Brown) pushed the boundaries of both philosophical and educational analysis.

Although I had expected to learn something new, I was not prepared for the issues that would confront me. I was forced to examine my own biography – that of a biologist and medical journalist – in the context of feminist, constructivist and post-structural thought. The assumptions underlying my knowledge and work were challenged. Also disrupted were the universalizing principles central to my beliefs in science and journalism. No longer could I consider knowledge as objective and value-free. Gone was the wall between the journalist and the observed. Never before had I considered the roles played by culture, society and gender in forming scientific tradition. My ideas about the nature and aims of inquiry were reeling. 5 But within this intellectual maelstrom, I found focus. I found a language that allowed me to articulate the concerns I felt when writing about health and medicine as a medical journalist. At the same time, this language raised new questions for me. I completed

5 To put it in the terms of Thomas Kuhn (1970), I had encountered a paradigm shift. Once crossed, I could never go back to the particular stance I previously held about knowledge and science.
my Master's degree in education and decided to pursue these questions further through a Ph.D. in interdisciplinary studies at UBC.

In March of 1997, I met with Dr. Michael Burgess, Chair of Biomedical Ethics, to discuss my doctoral program. He and Dr. Douglas Horsman, head of the Hereditary Cancer Program for the BC Cancer Agency, had applied for funding to conduct a comparative study of the ethical and moral dimensions of genetic risk for Huntington Disease and breast/ovarian cancer. Dr. Burgess asked me if I would like to participate. As I discussed the project with him, I realized it would provide an excellent opportunity for me to explore some of the questions that originally haunted me: What is health? What is illness? How are these issues defined and for what purpose? Genetic testing, in particular, provided the context to look at how a new medical technology might change current notions of health. I further wished to examine the ways in which people's moral positions took shape within a social and medical context dominated by particular ideologies. I began my Ph.D. in September 1997.

Organization of thesis

This thesis is arranged in nine chapters. Following the introductory chapter, Chapters Two and Three present a review of the literature. Chapter Two is largely descriptive. It focuses on scientific studies related to genetic testing for hereditary breast/ovarian cancer as well as describes the BC Cancer Agency's Hereditary Cancer Program. My purpose here is to summarize the current state of knowledge and practice regarding genetic testing and to highlight areas of inquiry left unresolved. Chapter Three selectively examines the ethics and social science literature on the benefits/harms of genetic testing for hereditary cancers. I also pay special attention to the literature that helped shaped the conceptualization of this study. Chapter Four details my methodological approach, as well as the procedural aspects relevant
to the study. Study findings are presented in Chapters Five, Six and Seven. Chapter Five situates the analysis by focusing on how individual and familial experiences with hereditary breast/ovarian cancer contribute to different knowledges about the disease. In Chapter Six, I explore participants’ reasons for genetic testing, focusing on agency and conceptions of self. Chapter 7 extends the analysis by evaluating the impact of genetic information on moral agency and understandings of self. In Chapter Eight, I discuss the key themes arising from the study. My purpose is to show people’s experiences and accounts of genetic testing can be analyzed as sites of valuable philosophical reflection and critical analysis. Chapter Nine concludes the thesis with a summary of the key research findings and discusses their implications for ethics and clinical practice.
CHAPTER 2:
Exploring the Scientific and Clinical Landscape

Let the data speak for themselves, these scientists say. The trouble with that argument is, of course, that data never do speak for themselves.

--- Evelyn Fox Keller, Reflections on Gender and Science

Introduction

Breast cancer has become a disease of enormous medical, social and political importance in Canada, the U.S. and other industrialized nations. Rising rates and minimal decreases in mortality have resulted in large numbers of women living with and dying from the disease. In Canada alone, it is estimated that 20,500 women will be diagnosed with breast cancer this year and 5,400 will die from it (National Cancer Institute of Canada, 2002). These and similar figures have given rise to labels for breast cancer such as a “crisis,” an “epidemic,” a disease that “is out of control” (Lantz and Booth 1998).

Within this context, the discovery of a genetic marker for breast cancer has been heralded as a major breakthrough. Researchers and clinicians posit that knowledge of mutation status may enable women to take action before the disease occurs. This chapter aims to provide an overview of the empirical literature on genetic testing for hereditary breast/ovarian cancer. The review is primarily descriptive in nature, with the literature drawn from the fields of medical genetics, psychology and genetic counselling. Its focus is on how genetic knowledge is constituted from the perspective of scientists and medical specialists working in this area.

The first section begins with a description of this hereditary cancer syndrome, comparing it to what is known about sporadic breast/ovarian cancer in the general
population. It situates genetic testing scientifically by sketching the advances that underlie the technology. It also explores the benefits and limitations of testing. In section two, I review the clinical literature on the psychosocial effects of genetic testing. This literature largely comprises quantitative survey studies aimed to assess attitudes and the psychological impact of providing genetic risk information. I critique the strengths and limitations of this research and identify where gaps in knowledge remain. Section three discusses some of the qualitative studies conducted on this syndrome. In the final section, I provide a descriptive account of the Hereditary Cancer Program at the BC Cancer Agency in order to provide context for the study, as well as to situate this program (its guidelines and counselling practices) within the broader scientific and political context of which it is a part.

Before proceeding, however, I wish to point out that my review of the genetics literature does not include a critique of scientific concepts themselves. A number of scholars, for example, have taken scientists to task for their use of concepts such as risk, susceptibility and genetic inheritance. By identifying the “constellation of meanings” (epidemiological, medical and popular) surrounding risk, Gifford (1986) has done much to show how notions of risk are socially and culturally constructed. Others have illustrated how “risk” is a heavily value-laden term, which shapes not only choice of research topic, but how research data are gathered and evaluated (Lippman 1991; Sherwin and Simpson 1999; Simpson 2000). While their work lends insight into the ideological underpinnings of scientific terms and research, I wish to begin this dissertation where the participants did themselves: with notions of heredity.

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6 Some of this review may seem may seem weighty in scientific details. However, as will be explicated later in the dissertation, I strongly believe that knowledge of the science underlying genetic testing (even if this is a social construction) is crucial if we are to better assess the benefits, limitations and efficacy of this technology.
and genetic risk information based on uncertain, but current western scientific thought. I maintain the latter is integral to understanding the evolving context of genetic testing programs.

Breast/Ovarian Cancer: A Hereditary Cancer Syndrome

Throughout the centuries, people have known that certain characteristics “run in families.” But how, why and with what probability eluded scientists until Gregor Mendel conducted his research with plants during the last part of the nineteenth century. Ever since, geneticists have sought to understand how physiological variations, disease, behavioral traits and mental disorders were inherited. The Human Genome Project, an international effort to identify and sequence all the genes in the human genome, is considered a major advancement in this regard. Launched in 1990 with an expected completion date for 2003, it has become a central feature of cultural, scientific, political and economic landscapes of numerous nations. Major investments are being made to find new treatments through the development of gene

7 At the same time, I wish to stress that I concur with Harding (1993, 1991), Keller (2000) and other philosophers of science who state that scientific knowledge – like all knowledge – is never neutral. We pursue certain kinds of knowledge in certain contexts under various social, political and intellectual pressures. Science is a social enterprise shaped by history and the language developed for this disciplinary field. It offers a particular lens through which we view the world.

Wittgenstein’s description of ethics has helped me think through this further. He wrote “Ethics does not treat of the world. It is a condition of the world, like logic” (Notebook 1914-1916). Following his line of thought, I would argue that science does not provide an objective reflection of the world but is a condition of the world, like religion.

8 A working draft of the complete human genome was announced, with much publicity and fanfare, in 2000. The target date of making the complete high-accuracy sequence available is April 2003 (User’s Guide to the HGP, 2002).
therapies, biopharmaceutical and other novel gene technologies (Health Canada 2001).\(^9\) It is within this era of molecular genetics that genetic testing for breast/ovarian cancer falls.\(^{10}\)

It has long been known that cancer is genetic, meaning that transformation of a normal cell to invasive and malignant growth is caused by changes in the DNA (King, Rowell et al. 1993; Elwood 1999; Clark 2000). However, most cancer is genetic due to somatic or non-inherited events; cancer results from accumulated changes or damage to one or more genes at the cellular level rather than being transmitted by sperm or egg (Elwood 1999). Thus much of what is genetic in cancer is not hereditary (King, Rowell et al. 1993).

But researchers have also been aware that certain cancer syndromes, such as breast, ovarian, colon and prostate cancer, cluster in families (Lynch 1967; Lynch, Lynch et al. 1970; Lynch 1972). Indeed, current estimates indicate that between 5% and 10% of breast and ovarian cancers are caused by an inherited predisposition (Newman, Millikan et al. 1988; Clauss, Risch et al. 1991). These hereditary types of breast/ovarian cancer are syndromes of cancer susceptibility that are transmitted from parent to child. Researchers use various criteria to identify individuals at risk for hereditary cancer, “but all require several cases of breast or ovarian cancer among near relatives in the same line of descent” (Koenig et al., 1998). Other features include a younger age of onset (premenopausal cancer), an increased frequency of bilateral cancers or multiple primary sites, increased risk in conjunction with increased number of family members, and a strong association with ovarian cancer (Easton 1995;)

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\(^9\)The $3\text{-}\text{billion U.S. Human Genome Project enlisted scientists from 18 countries. They used supercomputers to generate an ordered list of the three billion nucleotides that make up the "human genome." It was thought that the mapping of the human genome would advance diagnosis and development of new treatments for disease. Yet, the completed draft DNA sequence is mostly unintelligible. What lies ahead for scientists is the far more complex task of identifying the 30,000-odd genes found within, and deciphering what they do and how they do it (Keller, 2000; Weir, Lawrence & Fales, 1994).\

\(^{10}\)Estimates suggest that one in 400 women aged between 25 and 55 carries one of the susceptibility genes (BRCA1 or BRCA2) for breast cancer, making this the most prevalent disease gene for which genetic testing could be available in the future (Clauss et al, 1991; Ford et al, 1995).
Researchers have identified two primary genetic factors that contribute to breast cancer. The first is genetic linkage to breast cancer, which was first established in 1990 by Mary-Claire King and her colleagues (Hall, Lee et al. 1990). They found that a locus on chromosome 17 accounted for cancer susceptibility in 45% of 23 breast cancer families studied. In 1994, the gene, BRCA1, was identified and cloned (Miki, Swenson et al. 1994). The following year, a second breast cancer susceptibility gene, BRCA2, was located on the long arm of chromosome 13 (Wooster 1995). These genes are extremely large, with several hundred distinct mutations documented for both BRCA1 and BRCA2 (Wooster, Neuhausen et al. 1994; Wooster 1995; Elwood 1999). Thus, a family may have a unique mutation that differs from mutations found in other families.11 In addition, some mutations have been associated with specific ethnic backgrounds. For example, three mutations — 185delAG and 5382insC in BRCA and 6174delT in BRCA2 — are associated with an Ashkenazi Jewish ethnicity and have been shown to account for a large proportion of hereditary breast/ovarian cancer cases in this group (Olopade 1997; Struwing, Hartge et al. 1997; Hartge, Chatterjee et al. 2002). Specific founder mutations have been connected to populations in Quebec, Poland, Scotland, Iceland and Finland as well (Tonin, Mes-Masson et al. 1998; Gordski, Byrski et al. 2000; Liede, Cohen et al. 2000; Neuhausen 2000; Sarantus, Huusko et al. 2000).12

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11 This situation is quite different from some single-gene disorders, such as Huntington Disease and sickle cell disease. These involve the mutation of just one base pair, which is the same in all carriers (Clark, 2000).
12 Founder mutations refer to mutations that arise from a common ancestral origin and occur in high frequency within certain populations because of historic isolation or lack of mobility (Bergman et al, 2001). Other diseases linked to a founder mutation within a specific population include sickle cell anemia (carried by 1 in 10 blacks); Tay-Sachs disease (carried by 1 in 25 Ashkenazi Jews; familial hypercholesterolemia (carried by 1 in 100 French Canadians) (Friedman et al, 1996).
BRCA mutations are inherited in an autosomal dominant manner. This means that transmission of the mutation occurs from generation to generation and each child (of a carrier) has a 50% chance of inheriting the mutation (Friedman, Dill et al. 1996). Unlike single-gene syndromes that follow the laws of simple Mendelian genetics, however, a BRCA1/2 defect does not denote absolute certainty but an increased probability of getting the disease. Researchers have applied Knudson's (1971) “two-hit” hypothesis to explain how an inherited predisposition to cancer works. In comparison to people who inherit two normal alleles for the BRCA gene, carriers are usually heterozygous for the mutation; that is they inherit one normal allele and one defective allele of the same gene. The normal copy of the gene permits functioning of the cell, but if it sustains a mutation, the cell has no back-up system (Clark, 2000). Thus, the “first” hit results from inheriting a damaged gene and the “second” hit is caused by additional damage to the remaining normal gene. Compared with people without this syndrome, a person who has an inherited mutation is at increased risk of developing cancer at an earlier age and in multiple sites (Clark, 2000; Friedman et al., 1996). These genes are thought to play an important role in DNA repair and tumor suppression (Offit 1998; Clark 2000; Hartman and Ford 2002).

Indeed, BRCA1/2 mutations confer a risk of breast or ovarian cancer substantially higher than most women face. Initial studies in high risk families indicated that women who inherit a mutation of either gene have a 56% to 87% risk of getting breast cancers by age 70 (Easton, Bishop et al. 1993; Easton 1994; Ford, Easton et al. 1994). The same mutations confer a 16% to 44% risk of contracting ovarian cancer by age 70 (Ford, Easton et al. 1994; Huntington Disease and cystic fibrosis provide examples of diseases that follow simple Mendelian genetics. In these instances, if one abnormal allele of the gene has been inherited, the person will get the disease. Knudson developed this hypothesis to explain why hereditary retinoblastomas usually exhibit an earlier age of onset and multiple occurrence more often than sporadic retinoblastomas (Knudson, 1971) His theory has been applied to other hereditary cancer syndromes as well (Friedman et al, 1996; Offit, 1998)).
Struwing, Hartge et al. 1997). More recent population-based studies suggest the risk may a little less than initially proposed: a 73.5% risk of breast cancer by age 80 and a 28% risk of ovarian cancer (Whittemore, Gong et al. 1997). Nonetheless, whichever estimates are used, the penetrance of these germline mutations is high.\footnote{Penetrance is the extent to which a gene is expressed (Richards, 1996). Genetic mutations predisposing to breast and ovarian cancer are highly, but not fully penetrant, meaning that not everyone who has a mutation will actually be affected by the disease (Ponder, 1997). In comparison, the genetic mutation for Huntington disease is considered to be fully penetrant since anyone who inherits this mutation will develop the disease.} In contrast, the corresponding population risk for North American women to develop breast and ovarian cancer is 10% and 1.4% respectively (Greene 1997; Foulkes and Narod 1998). Both men and women can be carriers for BRCA mutations, but it appears that only the BRCA2 mutation poses an elevated risk of male breast cancer. Men who inherit this mutation have approximately a 6% lifetime risk of getting breast cancer versus a background risk of 1 in a thousand (Easton 1997; Struewing, Hartge et al. 1997). There is some evidence to suggest, however, that BRCA1 and BRCA2 mutations may put men at a slight increased risk for developing other cancers, including prostate and colon cancer (Breast Cancer Linkage Consortium, 1999; (Ford, Easton et al. 1994; Struewing, Hartge et al. 1997; Olopade and Fackenthal 2000).

Despite the recognition that genetic susceptibilities exist, researchers caution that cancer is a multistep disease with a multifactorial etiology (Wild and Kleihues 1996). Multiple factors—environmental, hormonal or interactions with other genetic factors—are necessary for the disease to become manifest (Lerman 1997). Among the contributors to human cancer are exposure to environmental carcinogens, ionizing and nonionizing radiation, chronic inflammatory states (viruses and parasites), smoking and other factors that are genetic but not inherited (Friedman, Dill et al. 1996; Clark 2000; Rebbeck, Lynch et al. 2002). There is increasing evidence that these etiologic factors may interact with each other,
resulting in more than additive cancer risk (Wild and Kleihues, 1996). Epidemiological data also point to the role of environmental and behavioral factors in contributing to BRCA1/2 associated cancer. Reproductive history (early menarche, later age at first live birth or no children) and exogenous hormone use have been implicated as risk factors for breast cancer in the general population and in BRCA1/2 associated cancers as well (Rebbeck, 2002). Similarly, genes involved in hormone metabolism (e.g. oral contraceptives) have been linked to altered breast cancer risk in the general population, but their general contribution to risk in gene mutation carriers is less clear (Hopwood 1997; Rebbeck 2002). Despite these associations, however, there is increasing awareness that individual response to environmental agents may depend to an extent on the genetic background of the individual and the population. Thus, the integration of exposure, biological effect and genetic susceptibility into epidemiological studies is required to assess the relative contribution of these various parameters to cancer onset (Wild and Kleihues, 1996).

**Benefits and limitations**

In the medical literature, discourses around genetic testing for breast cancer tend to revolve around two main themes: the 'discourse of great promise' and 'the discourse of concern' (Durant 1996). The discourse of great promise suggests that genetic testing will be of benefit to persons concerned, as well as society, because it will permit more rational targeting of preventative actions. Advocates of the technology promote genetic testing on the premise that women found to have the mutation can potentially reduce their cancer risks by using early detection strategies (Muto, 1997; Olopade, 1997; Ponder, 1997). This may take the form of increased surveillance such as breast self-examination, annual clinical breast examination and mammography. Ovarian sonography along with monitoring blood levels of
CA-125 (a marker indicating the presence of tumor cells) has been recommended for early
detection of ovarian cancer (Burke 1997). The rationale for screening high-risk women is that
cancer may be detected at an early stage when the prognosis is better. Alternatively, it is
proposed that women may decrease their risks by undergoing prophylactic surgery (bilateral
mastectomy and/or oophorectomy) or chemoprevention (tamoxifen and potentially raloxifene
treatment) (Burke 1997; Foulkes and Narod 1998; Koenig, Greely et al. 1998).

The promise of genetic testing has been tempered, however, by a discourse of
concern. Traditionally, genetic testing has been applied to well-defined monogenic
syndromes that follow the laws of simple Mendelian genetics, such as Huntington disease or
cystic fibrosis. In these instances, if the gene has been inherited, the person will eventually
get the disease. With susceptibility testing for hereditary cancer, however, genetic
information is “probabilistic and uncertain” (Lerman, 1997; p. 4). Genes predisposing to
breast and ovarian cancer are not fully penetrant. To give rise to cancer, other factors
including exposure to environmental agents, hormones or inappropriate diet may be required.
Thus inheritance of an altered breast cancer gene is not sufficient to produce cancer (Lerman,
1997; Koenig et al, 1998; Lippman, 1998). In other words, if a woman from “a cancer prone”
family tests positive for a BRCA1 mutation, it does not mean that she will definitely develop
cancer.

Genetic testing for breast cancer poses other problems as well. To begin, BRCA1 and
BRCA2 are not the only genes that may predispose an individual to breast cancer. If a person
tests negative, it is unclear whether that is because a mutation is not present, or whether the
individual has a mutation that has not been found. Thus, a negative BRCA1 test result will be
meaningful in high risk families only if an affected relative is known to carry a germline
mutation (Sutcliffe 1999). In other words, the absence of the BRCA1 mutation does not confer the absence of risk. Indeed, scientists suspect that BRCA1 and BRCA2 are not the only genes, which may predispose an individual to breast cancer (de Jong, Notle et al. 2002). Another candidate gene, CHEK2 for example, has been localized on chromosome 22q (CHEK2-Breast Cancer Consortium, 2002). Yet, how much this contributes to hereditary cancer predisposition – and in which ways – is currently unknown.

Genetic testing for hereditary cancer is further limited by the availability of effective medical interventions (Koenig, Greely et al. 1998). Mammographic screening is routinely recommended for high-risk women, but studies indicate that at younger ages, its sensitivity is much lower \(^{16}\) (Fletcher, Black et al. 1993; Ferguson 1997). Also of concern are the possible iatrogenic effects of radiation exposure in women with these or other genetic mutations (Burke 1997; Cuckle 1998). It is widely known that current methods for screening the ovaries are inadequate. Studies continue to demonstrate that early detection of ovarian cancer with ultrasound is poor (Haber 2002; Kauff, Satagopan et al. 2002).

Technical procedures and the inter-comparability of laboratory results also pose another challenge for clinicians (Sutcliffe 1999). In order to shorten the time of testing, for example, a number of labs use a protein truncation test as their technique of choice (Noorani and McGahan 1999). Although this method is much faster than sequencing the entire gene, it is known to miss some mutations (Hogervost, Cornelis et al. 1995). Other provincial labs (for example, Quebec) use genetic tests designed to find only certain mutations because of their high incidence in the population served (Dr. Douglas Horsman, personal communication). Thus, the sensitivity and specificity of genetic testing may vary according to the specific lab

\(^{16}\) Although well established for older women, the efficacy of mammography screening in women younger than age 50 remains controversial. An NCI workshop concluded that mammography screening offered no benefit in women under age 50 (Fletcher et al, 1993).
in which the test is conducted. Specialists in the field have called for a standardization of genetic test procedures.\textsuperscript{17} However, in the meantime these examples show that not only are the meanings from the tests socially constructed, but so are the tests themselves.

**Prevention strategies**

To date, guidelines on surgery and prophylactic measures have been largely based on medical opinion. Prophylactic bilateral mastectomy, for example, is considered one of the management options for high-risk women even though scientific evidence proving its effectiveness has been lacking (Burke 1997; Koenig, Greely et al. 1998; Eisen and Weber 2001). The procedure has generated considerable controversy because of the paucity of evidence showing long-term benefit, among other things.\textsuperscript{18} Yet, recent studies are beginning to yield evidence that prophylactic surgery does indeed reduce the onset of both breast and ovarian cancer in women with known BRCA1/2 mutations.

The first of these studies took place at the Rotterdam Family Cancer Clinic in the Netherlands. Meijers-Heijboer and colleagues (2001) conducted an evaluation of 139 women with a BRCA1 or BRCA2 mutation who were enrolled in their breast-cancer surveillance program. At the time of enrollment, none of the women had breast cancer. Seventy-six of these women chose to have prophylactic mastectomy, and the other 63 remained under regular surveillance (This comprised a monthly breast self-examination, a semi-annual breast examination by a health care professional, annual mammography and later MRI was offered). At three-years follow-up, no breast cancers were observed in the 76 women who underwent

\textsuperscript{17} Dr. Doug Horsman, director of the HCP at the BC Cancer Agency, initiated a November 2002 workshop with other provincial hereditary cancer programs to develop consensus policy guidelines for hereditary cancer programs. Guidelines for laboratory testing will focus on quality assurance of mutation analysis (specimen handling, requisitions, testing protocols, internal QC measures, and external QC program - interprovincial and/or national).

\textsuperscript{18} See Eisen and Weber (2001) for a good review of this area.
prophylactic bilateral mastectomy, whereas eight were detected in the surveillance group. Researchers at the University of Minneapolis reported similar findings [Hartmann, 2001 #221. They conducted a retrospective study of the results of prophylactic bilateral mastectomy in 639 women at high risk for breast cancer. Twenty-six of the original group were later found to be BRCA1/2 mutation carriers. Retrospective analysis showed that the number of predicted cancers and deaths far exceeded the number of those observed. This indicated a 90% reduction in expected breast cancer incidence and mortality due to prophylactic surgery. Moreover, none of the 26 carriers, who also underwent surgery, developed breast cancer after a follow-up of approximately 13.4 years. Two additional publications show the benefit of prophylactic oophorectomy in preventing ovarian cancer, as well as in reducing the risk of breast cancer in women with BRCA1 or BRCA2 mutations (Kauff, Satagopan et al. 2002; Rebbeck, Lynch et al. 2002)). Clearly, further outcome studies based on long-term follow-up are needed, but together these publications provide mounting evidence that prophylactic surgery is effective in reducing breast/ovarian cancer risk (Eisen and Weber 2001).

Chemoprevention with tamoxifen also holds some promise for the future (Evans, Skizynia et al. 2001). Although the numbers are small, recent subgroup analysis of the National Breast Cancer Prevention Trial (NSABP P1 trial) suggests that tamoxifen reduces breast cancer incidence among healthy BRCA2 carriers, but not among healthy women with inherited BRCA1 mutations (King 2001).19 This will be an important area to follow if the

19 These findings parallel what has been found for sporadic breast cancers in general. In randomized trials, tamoxifen has been shown to be effective in treatment of estrogen receptor positive (ER+) tumors but not of estrogen receptor negative (ER-), in terms of prevention of recurrences, new primary tumors and fatality (Early Breast Cancer Trialists’ Collaborative Group, 1998). In sporadic breast cancer, the majority of tumors are ER positive whereas the opposite is the case in cancers diagnosed in women with high risk mutations in the BRCA1 genes (Johansson et al, 1997; Armes et al, 1999). The proportion of estrogen positive tumors is higher for BRCA2 mutation carriers (Duffy & Nixon, 2002).
data are confirmed using larger sample sizes. Yet, the benefits of chemoprevention must also
be weighed against its potential harms. While decreasing breast cancer risk, tamoxifen has
been associated with an increased risk of endometrial cancer and venous thromboembolic
disease (Evans, Skizynia et al. 2001). Further, there are no long term follow-up studies of its
use in premenopausal women.\(^\text{20}\)

**Psychosocial Implications of Testing**

While researchers have identified several limitations of genetic testing for hereditary
breast/ovarian cancer, of most concern is the potential for psychosocial harm (Biesecker
1997; Croyle, Smith et al. 1997; Lerman 1997; Croyle and Lerman 1999; Shaw, Abrams et
al. 1999; Kash, Dabney et al. 2000; Evans, Skizynia et al. 2001).\(^\text{21}\) At issue are the possible
deleterious effects that testing and test results might have on an individual’s social and
psychological well-being. The research contains several dimensions but generally focuses on
two main themes. First, what are people’s attitudes towards genetic screening for breast
cancer; how strong is their interest and what are their motivations for wanting testing?
Secondly, what is the psychological impact of seeking and living with this kind of risk
information? These questions have produced a great number of quantitative studies,

\(^{20}\) I thank Dr. Barbara McGillivray for bringing my attention to this point.

\(^{21}\) An interesting question to ask is whether genetic testing for other hereditary disorders prompts similar
attention to psychological issues (i.e. cystic fibrosis, sickle cell anemia and thalassemia. Psychological studies
in Huntington Disease have been based on the concern that predictive information may lead to suicide in some
cases). I raise this issue given the huge body of literature on the psychological implications of breast cancer
alone. The earliest research focused on the question: *What is the rate of psychological disorders in breast cancer
patients and moved to quantitative measures of coping (Myerowitz, 1980)*. Research has described in statistical
terms psychological reactions to the diagnosis of breast cancer; psychological reactions in the perioperative
period; psychological reactions to chemotherapy, radiation therapy and recurrence (Bloom et al, 1987;
1991; Payne et al., 1996); psychological reactions to advanced disease and psychological reactions of the breast
cancer survivor (Payne et al, 1996; Vinokur et al, 1990). The effect of mastectomy on body image has also
provided a topic of enduring research interest (Polivy, 1975; Myerowitz, 1980; Cohen, 1982; Derogatis, 1986;
Penman, 1987; Mock, 1993; Reaby et al, 1994; Schover, 1991, 1994, 1995; Vandervord, 1994). Do other illness
types prompt similar consideration or is much of this driven by the tendency of western culture to automatically
associate breasts with femininity and sexuality and thus a woman’s ‘psychological’ well-being?
conducted primarily by psychologists and health care practitioners. Qualitative studies, exploring the meanings people give to genetic information, are far fewer. Literature from both areas of research will be summarized in the following two sections.

**Attitudes towards testing**

Most studies examining the reasons why people want genetic testing rely on survey data obtained in response to a hypothetical offer for genetic testing (Lerman, Kash et al. 1994; Chaliki, Loader et al. 1995; Julian-Reynier, Eisinger et al. 1996; Lerman 1996; Andrykowski, Lightner et al. 1997). Interest in genetic testing among family members of breast and ovarian cancer patients has been mixed. Early indications suggested that over 90% of women offered a BRCA1 test would take up the option (Chaliki et al., 1995; Julian-Reynier et al., 1996, Lerman et al., 1994). Among a sample of 121 first-degree relatives of ovarian cancer patients, the most commonly cited motivations for BRCA1 testing were to learn about one's children’s risks; to increase the use of screening; to be reassured; to take better care of oneself; and to make childbearing decisions (Lerman et al., 1994). These findings were supported in later studies of women with a family history of breast cancer (Lerman 1996; Brain, Gray et al. 2000). Yet others have reported lower levels of interest in individuals with a family history (Andrykowski et al, 1997) and still others have found no association at all (Donovan and Tucker 2000).

Interest in genetic testing, however, appears to also extend beyond those with familial cancer. In a review of the literature concerning genetic screening, Croyle and Lerman (1995) observed that most members of the general population, as well as those known to be at high risk, generally hold favorable attitudes toward genetic testing. Survey data collected from 982 women in a medical setting indicated that the vast majority of individuals were interested
in genetic testing for breast cancer (Chaliki et al., 1995). Women who expressed the most
interest in testing were those involved in regular health and breast cancer surveillance. In one
of the few studies to consider socioeconomic factors in shaping attitudes towards genetic
testing, Tambor and colleagues (1997) found that women who were younger than 60, white,
believed their family would benefit if they had a mammogram, and believed that regular
mammograms gave them a feeling of control over their health, were more likely to be
interested in testing than those who were 60 or older, African-American or other. Julian-
Reynier and colleagues (1996) also observed that women who were most interested in
genetic testing were those that had higher incomes and levels of education. Richards and
colleagues (1997) assessed screening for BRCA1 among Ashkenazi Jews and found that the
vast majority (94%) desired testing. In a later study, Philips et al. (2002) reported that desire
to contribute to research provided a strong motivating factor for BRCA testing in a group of
Canadian women of Ashkenazi Jewish descent. In a Canadian study of the general
population, Bottorff et al. (2002) found that women with a family history of breast cancer (at
least one first- or second-degree relative), more years of education and who were younger
(between 20 and 40 years of age) tended to be most interested in genetic testing. At the same
time, it is important to bear in mind that expressions of interest in genetic testing often do not
reflect actual participation rates (Cappelli, Surh et al. 1999; Bottorff, Rainier et al. 2002). 22
Prior studies have revealed a discord between expressed interest and uptake of other genetic
tests, such as Huntington’s disease and cystic fibrosis (Crauford, Kerzin-Starrar et al. 1989;
Tambor, Bernhardt et al. 1994). Similarly, findings from the University of Wisconsin suggest

22 These findings also beg the question, to what degree is interest in genetic testing influenced by the availability
of a national health care insurance plan? A comparative study between the U.S. and Canadian experience would
be interesting here.
a similar trend for hereditary breast/ovarian cancer (Hartenbach, Becker et al. 2002). Of 125 families who met criteria for BRCA 1/2 testing, only 18% proceeded with the test.23

When researchers focused on psychological predictors, three factors influencing an individual’s cancer risk information-seeking behavior emerged: perception of vulnerability, level of anxiety or psychological distress and coping style (Bottorff, Ratner et al. 1996). In one study of the perceived demand for testing for susceptibility to breast, ovarian and colon cancer, most of the people surveyed anticipated that negative test results would improve their quality of life (83%) and make them feel less anxious, less depressed and more in control (Lerman, Kash et al. 1994). Perceptions of risk and cancer worry (rather than knowledge of personal risk factors) appear to be associated with greater interest in genetic testing for breast cancer. In another study, women anticipated potential anxiety if their results were positive (Julian-Reynier, Eisinger et al. 1996). “Some people mentioned that a positive test would turn them into a diseased person, a keeper of secrets, or would change their future or social relationships” (p. 733). Yet, it was also reported that many of the same women felt that positive results would motivate them to improve their health surveillance. They felt the benefits of genetic testing outweighed its disadvantages.

Other researchers looked at psychological distress as a motivating factor to undergo genetic testing. Some studies found that levels of anxiety and general distress among women at risk for breast cancer were higher than those found in the general population (Lerman, Kash et al. 1994; Valdimarsdottir, Bovberg et al. 1995; Cull, Anderson et al. 1999). Among individuals who had multiple relatives with breast or ovarian cancer, it was those who worried about cancer and who expressed mood disturbances, that were most likely to be

23 The HCP reports similar findings (Karen Panabaker, genetic counsellor, personal communication). Approximately one-third of those who receive genetic counselling for BRCA1/2 testing have the test.
interested in BRCA1 testing (Lerman 1997). More recent work has turned to the question of whether genetic counselling influences levels of distress and cancer worry. The results have been mixed with some studies indicating reduced distress and others no change (Cull, Anderson et al. 1999; Watson, Lloyd et al. 1999; Kent, Howie et al. 2000; Bish, Sutton et al. 2002; Brain, Norman et al. 2002).

Understandably, not all people wish to know whether they are at increased risk for a disease that has taken a devastating toll on their families. Yet, there is a dearth of information on people's decision-making reasons for choosing not to be tested. I identified only two research studies that focused mainly on individuals who refused testing (Geer, Ropka et al. 2001; Biesecker et al. 2000b). Conducted at the Cancer Centre, University of Virginia, Charlottesville, Geer and colleagues identified the following reasons for not seeking testing: a) concerns about becoming uninsurable; b) fears that testing would be emotionally upsetting for self and family; c) no perceived benefit and d) time commitment. In a related study, Biesecker et al. (2000b) found that individuals who declined testing were more likely to be younger and to have lower levels of family cohesiveness than those who sought testing. This group noted that previous research (Friedman, Baer et al. 1988) on cohesive families suggest that the latter are generally more resilient to stressful life events such as breast cancer. While this work provides some insight into reasons why people decline testing, caution should be exercised in interpreting these results because of their small numbers.

Psychological distress

In addition to attitudes and psychological motivation towards genetic testing, there is a large and expanding body of literature on the psychological impact of receiving BRCA1/2 test results. Underlying this research is the expectation that some individuals will react with
concern, anxiety or even depression when informed they are at increased risk for developing a disease (Shaw, Abrams et al. 1999). Two studies assessed the short-term psychological impact of BRCA1/2 testing among research families. Lerman et al (1996) reported that one month after disclosure, individuals who received negative results exhibited decreased depression and role impairments. Participants who obtained positive results showed neither increased nor decreased distress. In short-term follow-up of 60 women tested for a BRCA1 gene mutation, Croyle et al (1997) also found that negative test results reduced people’s anxiety. Those who received positive results did not exhibit an increase in distress, but they did show significantly higher levels of test-related anxiety than non-carriers. These findings have also been substantiated by a more recent study in which 279 women were assessed six months after receiving their test results (Schwartz, Peshkin et al. 2002). Again, women who tested positive for the mutations did not exhibit increased psychological distress, while those who received negative results reported a significant reduction in anxiety and concerns related to their perceived risk.

While these findings indicate that genetic testing does not lead to increased anxiety for most people, other data suggest that certain subgroups may be more vulnerable. In a follow-up study of BRCA 1/2 and p53 carriers,24 Dorval et al (2000) found that most participants were accurate in anticipating emotional reactions to test results and did not experience psychological distress. On the other hand, a few individuals who underestimated their emotional reactions to the results showed an increase in anxiety at the six month follow-

24 P53 testing is a genetic test used to diagnose and/or predict Li-Fraumeni cancer syndrome. Li-Fraumeni is an inherited syndrome that predisposes families to breast cancer, in association with sarcomas and other cancers occurring at unusually early ages (Birch, 1992).
up. Affected BRCA1 carriers, in particular,\textsuperscript{25} reported higher levels of worry, anger and/or sadness than they had anticipated. Bish et al (2002) also found differences in response to genetic test results when comparing unaffected women with those who had previously had cancer. On the whole, women who had already been treated for cancer exhibited more concern about developing ovarian cancer and felt more at risk of developing breast cancer after counselling than those who had not had cancer. These findings contradict previous research, however, which found that the highest levels of distress occurred among mutations carriers with no prior cancer diagnosis or preventative surgery (Kash, Dabney et al. 2000). Further, there is a paucity of research examining the reactions of people to indeterminate results.\textsuperscript{26} Indeed, experience from Huntington disease indicates that ambiguous results can be more stressful than positive results (Wiggins, Whyte et al. 1992).

**Limitations of psychological studies**

Despite the efforts made to assess the psychological impact of genetic testing, these studies have been hampered by inconsistencies. A major problem methodologically is that different assessment tools have been used for measuring psychological distress [Bish, 2002 #231; Coyne, 2000 #236; Hopwood, 1998 #238]. As Bish et al. (2002) state, some are specific to anxiety or depression (e.g. Hospital Anxiety and Depression Scale; Beck Depression Inventory; State-Trait Anxiety Inventory). Others evaluate more general psychiatric distress (e.g. General Health Questionnaire). And still others are specific to cancer (e.g. Cancer Worry Scale; Impact of Events Scale). Further, some researchers have

\textsuperscript{25} In their study sample, none of the people suspected of having inherited Li-Fraumeni cancer syndrome suffered from cancer.

\textsuperscript{26} Recall that negative results are considered true negatives only if a tested person does not carry a previously identified family mutation. Otherwise, negative results are considered inconclusive or indeterminate because the individual might have a mutation that has not yet been found. Variants or ambiguous tests results refer to alterations in a specific gene that are of unknown or unclear clinical significance (Friedman et al, 1996).
relied on self-report assessment in determining psychiatric distress and others employed interview-based evaluation (Coyne, Benazon et al. 2000). Comparison between these survey studies is further compromised by the variation in inclusion criteria (Bish, Sutton et al. 2002). Some studies involved women who previously had breast/ovarian cancer. Others did not. Moreover, the absence of longitudinal studies does not take into account how people's reactions to genetic risk information may change over time.

Studies focusing on psychological predictors also tend to overlook the wide range of experiences that contribute to a person's perceptions of hereditary cancer and cancer risk. There is a scarcity of literature, for example, examining the experience of genetic testing from the perspectives of individuals and their families. As McKellin (1995) observed with childhood deafness, psychological studies have a propensity, consistent with their professional orientation, to view a person primarily in terms of her/his illness. They typically ignore the influence of family and social context in shaping people's responses to health information. Indeed, besides its inclusion as a major risk factor, none of the above studies examined the impact of particular family experiences with cancer (e.g. the number of cancer deaths or care-giving roles) on emotional/psychological distress. Neither did they give consideration to the influence of other family members (e.g. reactions of parents or siblings who has previously undergone testing) in shaping interpretations and reactions to test results. Also unrecognized in these studies is how practitioners' personal attitudes towards genetic testing may affect counselling practices. Professional backgrounds, service protocols for communicating risk information, counselling styles and even providers' personalities and biases will shape how genetic information is delivered and likely received. Further, as educational theorists have argued for some time, not all learners are the same. Counselling
needs to take into account, for example, that some people learn best by auditory means; others are visually orientated and still others learn by teaching themselves (Eisner 1985; Eisner 1994). Thus, the simple assumption that psychological assessment can accurately gauge participants’ post-disclosure distress hardly begins to get at the complexity involved in people’s understanding of and responses to genetic testing.

Finally, by using quantitative surveys, this type of research presents women with an already defined framework of meaning and measures. The concepts and categories studied are those considered to be salient by the researcher, rather than by those who are participating in the study. Hence, it is often difficult to know whether by asking closed questions or measuring certain variables, the data accurately explain the issues being examined (Waxler-Morrison, Doll et al. 1995). It precludes “the gathering of the patient’s perspectives on the issues being examined” (Rosenbaum and Roos 2000:156). Indeed, it could be argued that survey studies provide very little information about what people from hereditary cancer families think is most important to them. A language, which focuses solely on depression, anxiety and psychological distress, may fail to capture the many ways in which people might understand genetic risk.

People obviously incorporate information into a framework of pre-existing knowledge and beliefs. Attitudes to genetic information are likely to vary with personal experience, family history, access to counselling services, cost and other situational factors. In furthering our understandings of individuals and families reactions to genetic risk, these various experiences must be taken into consideration. These issues warrant far more attention to individual, family and social context than quantitative techniques allow. This is not to suggest that quantitative survey studies have no utility. This work has added to our
understandings of some parameters of living with genetic risk. Yet, research on the psychosocial aspects of predictive genetics can be strengthened by a strategy that combines a variety of theoretical and methodological approaches. Clinical assessments should include measures of outcome, but interview-based studies are needed to tease out the sensitive and complex issues first. I now turn to the literature that utilizes qualitative methodology.

**Qualitative Studies**

In exploring meanings around genetic testing, a small (but growing) body of qualitative research adds to the understanding of the impact of genetic information on people’s lives. Much of this literature is descriptive, and overlaps with questions posed in the quantitative surveys: What are women’s attitudes and responses to genetic testing for hereditary breast/ovarian cancer? Who accepts the offer of testing and why? Some publications have also addressed women’s interest in genetic testing within the broader social and political ideologies of risk and genetic inheritance (Finkler 2000; Press, Fishman et al. 2000). In taking a meaning centered approach, however, most of these publications point to the importance of belief or knowledge systems in shaping notions of heredity, risk and moral values within the cancer experience.

Indeed, Geller and colleagues (1997) conducted ten focus groups with women as part of an effort to improve models of informed consent. Their purpose was to obtain a better sense of women’s understanding of genetic testing, what they would want to know about testing if it were offered, and their reasons for such interest. The groups of women were at various levels of risk ranging from affected, to at-risk but unaffected, to the general population. They also came from a range of socioeconomic and ethnic backgrounds. Their findings showed that how patients understand factual information was contingent upon their
background assumptions and personal history (Geller, Bernhardt et al. 1995; Bernhardt, Geller et al. 1997; Geller, Strauss et al. 1997). For example, some people were wrongly informed about breast cancer; others reported fatalistic or superstitious beliefs about the likelihood of developing cancer. Still others perceived their risk as more exaggerated than it actually was. Stories, anecdotes and personal exposure to the disease resonated deeply in shaping a woman’s beliefs.

Women’s reactions to the offer of genetic testing also varied. Some women saw knowledge about genetic risk as empowering. Knowing what the future would hold, as well as being able to use the information to make life style choices (i.e. increased frequency of mammography or modifying risk factors such as diet and exercise) was viewed as a benefit. Some women at increased risk felt testing would relieve their anxiety of uncertainty. Conversely, other women anticipated that knowledge of having the BRCA1 mutation would cause significant personal stress. Still others perceived a benefit by just participating in research that could advance medical science. In a similar kind of study, Tessaro et al. (1997) also found altruism to be a major theme with regard to BRCA testing. They reported that women already diagnosed with breast cancer, in particular, felt a sense of obligation to be tested for other women and not just their relatives. This group of women said they would be interested in testing even if their results were withheld.

In addition to showing the profound effect of lived experience in shaping attitudes towards testing, some of these qualitative studies generated an unexpected finding. Geller and her colleagues observed that most participants were interested in BRCA1 testing until the uncertainties and limitations of the test were explained. When given information about the test itself, not just availability, interest waned dramatically. Tessaro (1997) also observed
increased ambivalence in women regarding BRCA1/2 testing following an education session. Only those who had strongly altruistic motives did not seem to lose interest. A recent survey study (Biesecker 2000b) supports these observations. In a study on genetics education and counselling for breast cancer, Biesecker et al. found that 69% of participants said that they would likely to undergo a genetic test if it was offered to them. Following education and counselling, this percentage dropped to 44%. Together these publications suggest a larger story than typically found in the biomedical literature. Women’s interests in genetic testing may be high initially, but may very well diminish once they know more about it. The strong sense of altruism some women may feel, however, also has implications for genetic testing and needs further exploration.

Genetic testing raises not only issues of whether to be tested or not, but questions of obligation, disclosure of information and responsibility to others. One recent study augurs the potential ethnography can make to this discussion. Green, Richards and colleagues (1997) interviewed 46 women attending a cancer genetics clinic in an effort to explore family communication after genetic testing for breast/ovarian cancer. The authors found that all participants recognized a duty to inform other family members of genetic risk. Some were prepared to go to some lengths to meet that responsibility, even when passing information was difficult. One woman was prepared to trace a daughter given up for adoption should she be shown to be a carrier of a genetic mutation. Yet, many women who felt they should inform, also struggled with a concern not to alarm. The words of one participant poignantly illustrate this concern:

It is very difficult...My cousin may not want to know about cancer. Or if she does, she may not want to talk about it with me necessarily. So it’s an area that I have to tread very carefully, because I don’t really want to upset or alarm her (Green, Richards et al. 1997: 52).
This woman’s words underscore the complexity of involving and educating other family members, especially when they are not prepared for discussion of complex genetic issues. Tessaro’s (1997) study also points to other conflicts that may arise with genetic testing. For many women, presymptomatic testing reinforces obligations to family. Women who had relatives with breast cancer, in particular, framed their discussion of genetic testing as a family experience. Many thought they “owed it” to their families to have all possible health-related information. Hallowell (1999) reported similar findings. She found that women who attended a genetics clinic for breast/ovarian cancer perceived themselves as having a responsibility to their family (past, present as well as future) to determine their genetic risks. Responsibility lay in managing their own health risks as well as in providing genetic risk information to other kin. A later study, focusing on women who already had breast/ovarian cancer, reinforced these findings (Hallowell, Foster et al. 2002). The main reasons given by these women for undergoing mutation testing were: to provide genetic information to other family members, uncertainty about the etiology of their cancer, general altruism and to obtain information that might facilitate risk management decisions.

The research conducted to date provides an important beginning to better understanding people’s responses to genetic testing for hereditary breast/ovarian cancer. Yet, aside from Geller et al.’s research on informed consent and Hallowell’s work on obligation, the dialogic between ethical analysis and qualitative research has failed to gain much attention. In particular, the relationship between moral agency and genetic information has gone unexplored. Yet, without a broader understanding of how genetic information may influence notions of agency and self, it is difficult to identify mechanisms that better address
people's needs. As Henderson (2001) has written, when ethical analysis is considered in light of qualitative data, "richer interpretations are possible" (p. 277).

**Current testing practices**

The first three sections of this chapter focused on the medical construction of hereditary breast/ovarian cancer and cancer risk. I looked at the scientific advancements underlying the genetic etiology of this syndrome and the research linked to the psychosocial aspects of the genetic testing experience. Yet, it is also important to remember that testing does not occur in the abstract, but occurs in an actual physical location with various people conducting and interpreting the tests. In this final section, I present a descriptive account of the BC Cancer Agency's Hereditary Cancer Program (HCP), in order to provide context for the study, as well as to situate this program (guidelines and counselling practices) within the broader scientific and political context of which it is a part.

**Clinical criteria: Who is eligible for testing?**

Until recently, genetic testing for breast cancer susceptibility has been offered only at major teaching hospitals and research centres in Canada (Sharpe 1997). Eligibility criteria vary between provinces, but testing is usually restricted to those with significant family histories of the disease or particularly early presentation. These programs have been designed to evaluate whether testing should be offered as part of routine care, as well as to determine the most appropriate methods of presenting risk information. Moreover, regulations, including the criteria for testing, are subject to constant change because of ongoing research and new developments (Sharpe, 1997).\(^{27}\) In this context, however, it is

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\(^{27}\) To my knowledge, this situation is not unique to Canada. That said, a workshop was held in November, 2002 in Quebec City, the aim of which was to begin to develop uniform standards and consensus in policies and protocols across Canadian programs. Specific areas included: Education and counselling issues, clinical disclosure, clinical management and risk reduction issues and database/registry issues.
important to note the distinction between genetic testing and genetic screening. Genetic screening involves the uses of genetic tests to evaluate populations or groups independent of family history (Noorani and McGahan 1999). Prenatal screening for trisomy 21 (Down syndrome) and newborn screening for phenylketonuria (PKU)28 are good examples of this. Genetic testing, on the other hand, involves the use of specific assays to determine the genetic status of individuals suspected of being at high risk for an inherited disorder because of family history (Noorani and McGahan, 1999). It is offered to individuals whose personal and/or family history suggests they are at increased risk for developing certain disorders and passing the genetic mutation onto their children (Henderson 2001). Genetic testing for hereditary breast/ovarian cancer susceptibility falls within this category. It is a test, not a screen.

The B.C. Experience

Given the recent discovery of the BRCA 1/2 genes, genetic testing for hereditary breast/ovarian cancer is a relatively new phenomenon. It was only in 1996 that the BC Cancer Agency and the BC Provincial Genetics Programme joined together to offer an education, counselling and testing program for persons with a strong family history of cancer. The Hereditary Cancer Program (HCP), located at the Vancouver Cancer Centre, began as a research program designed to investigate and develop a pilot project for genetic counselling and testing. Donated funds from the private British Columbia Breast Cancer Foundation enabled the research group to buy the necessary sequencing equipment and provide counselling services. Later in April 1997, the Ministry of Health created an official

28 PKU is an inherited disorder that can lead to mental retardation. It is caused by different mutations in the enzyme phenylalanine hydroxylase, which do not permit the amino acid phenylalanine to be degraded. Accumulation of the amino acid causes damage to the central nervous system and mental retardation. If detected early, the disorder can be treated successfully with appropriate dietary changes that limit phenylalanine intake (Friedman et al, 1996).
Cost Centre for the HCP to provide infrastructure support for nursing/education, genetic counselling, laboratory testing, as well as clinical follow-up, evaluation and assessment. Established under a research protocol, the HCP also aimed to provide a clinical service. Family physicians, gynaecologists or oncologists referred patients who were concerned about their family history of cancer. Surgeons also sought testing for patients to determine whether individuals with strong family histories were at sufficient risk to justify prophylactic mastectomy and/or oophorectomy.

The HCP’s testing protocol is based on a 20% prior probability of finding a mutation. This means that genetic testing is offered if a family history meets one of the following criteria: a woman with breast cancer diagnosed at 35 years of age or younger, ovarian cancer diagnosed at age 50 or younger, an Ashkenazi Jewish woman with breast or ovarian cancer at any age or a blood relative with a confirmed mutation of a cancer susceptibility gene (e.g. BRCA1 or BRCA2). Individuals may also be eligible for genetic testing if their family history supports two of the following criteria: cancer in two or more closely related family members, cancer at an earlier age than expected in the general population (e.g. breast cancer before menopause), multiple primary cancers in one individual, cancers associated with known hereditary syndromes and male breast cancer. The HCP’s testing protocol also stipulates that an affected family member (a person with breast and/or ovarian cancer) must be tested first, and a mutation identified, before any unaffected relatives can proceed with testing (see Appendix 1).

According to Dr. Douglas Horsman, HCP director, the decision to limit testing to families where there was a greater than or equal to 20% chance of finding a BRCA1 or 2 mutation reflected local considerations. The 20% level provided justification for not testing unaffected probands (people without cancer) as an index test, as the likelihood of finding a mutation in this group was suspected to be very low. If they used the 10% probability as their cut-off level, it would have been more difficult not to accept these patients. Accordingly, the volume of testing would have gone up and increased an already extensive backlog.
Genetic counselling for hereditary breast/ovarian cancer testing is based on protocols developed for predictive testing for Huntington Disease (Wiggins, Whyte et al. 1992). There is general consensus that genetic testing, either predictive or susceptibility testing, must be done in a supportive environment that includes counselling regarding the pros and cons of testing and the availability of formal psychosocial support (CCIS/NCIC, 2002). An important part of the genetic counselling process is to explain the principles of medical genetics, patterns of inheritance and risk probability (Peters 1998). At the HCP, the sessions begin with either a geneticist or genetic counsellor collecting information regarding family history of cancer in order to ascertain risk status. This is followed by careful pretest counselling about the medical, psychological, and economic risks and benefits of testing. The session covers standard items of informed consent for genetic testing and consideration of potential psychological effects of both positive and negative results on the participant as well as the subsequent impact on other family members. If participants meet eligibility criteria and consent to undergo testing, blood samples are drawn at the conclusion of this session.

At the time of this study, DNA sequencing and reporting of test results averaged 18 to 24 months for new cases and four to six weeks if a mutation has already been identified in the family (This, of course, is technology dependent. The HCP is currently seeking funds to purchase a new sequencer, which would enable much faster analysis and throughput of DNA samples). Tested persons are informed when their results are available. When ready, they meet again with the geneticist and genetic counsellor to receive their test results. If positive, the disclosure session includes a review of medical recommendations (screening and/or prophylactic surgery) and discussion of the possible individual and family impact of the test results. A patient also has the opportunity to meet with an oncologist, surgeon or another
physician at this time to discuss her medical options in greater detail to have continued surveillance through a Cancer Agency high risk clinic. From January 1998 to October 2002, the HCP received 3,969 referrals for breast/ovarian cancer (records were not kept previously). Of these, 3218 individuals received genetic counselling and 793 underwent genetic testing for BRCA1/2. Similar to the experience of other centres, BRCA 1/2 mutations are found in only a relatively small percentage of families. The detection rate currently stands at 21% for new cases. The remaining 79% are classified as having uninformative test results. (Recall a negative BRCA1 test result is meaningful only in high-risk families where a germline mutation has been previously identified. All other negative test results are considered indeterminate or uninformative in nature as geneticists do not know whether the person has another mutation that is responsible for the hereditary cancer in his/her family).

The political landscape

The HCP, like all medical programs, has been greatly impacted by the political landscape in which it has evolved. Between October 2000 and April 2001, Myriad Genetics, a U.S.-based company, was awarded a series of patents by the U.S. Patent Office that gave it extensive control over both BRCA genes (CCS/NCIC, 2002). Myriad has subsequently claimed a monopoly for the next 20 years on the whole of BRCA1 and most of BRCA2, any information derived from them, and all methods developed to diagnose and treat hereditary breast and ovarian cancer.

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30 This information was provided to me by Karen Panabaker, genetic counsellor, and Michelle Kelsey, BSc.RT. Laboratory Technologist, for the HCP. These are the most current figures as of October 24, 2002.

31 Detection of mutations of unknown significance is 2.6%. These mutations, called unclassified variants, are also grouped into the uninformative results category as their clinical significance is unknown (Michelle Kelsey, personal communication, January 2003).
Up until recently, genetic testing was offered as a health service (usually in the context of global program funding) by most provincial health ministries at no direct cost to the patient. DNA analysis was conducted locally. As of July 2001, however, Myriad Genetics, Utah, sent out a legal notice asserting its patent rights for the BRCA1 and BRCA2 genes and stated that all genetic testing for these genes must be sent to Myriad (Hurst 2001). This translated into a three-fold increase in cost to perform the test, ($3,850 Canadian) for the full sequencing of BRCA1 and 2 by Myriad, compared to approximately $1200 - $1500 for testing by the BCCA’s HCP laboratories. As a consequence of this legal action, the BC Ministry of Health Services directed the BC Cancer Agency to suspend local testing (Kent 2001). Patients who are eligible and are willing to pay for the test can obtain it through MDS Laboratories (the Canadian partner of Myriad Genetics). The Ontario government, on the other hand, has not suspended testing and said that it will legally challenge the patent (White 2002). European countries, including Belgium, Denmark, Germany, the Netherlands and the United Kingdom are preparing legally to oppose the patent as well (Love 2001; Wadman 2001). France has already launched a legal challenge (CCS/NCIC 2002). The BCCA has approached the Ministry of Health, stating that the ‘cease and desist’ order places B.C. in a position of providing a lower standard of care (regarding genetic testing) than other provinces. It will take some time before this problem is resolved.

In the meantime, Myriad has added more fuel to the fire by launching a direct advertising campaign to women to promote its genetic test for breast/ovarian cancer susceptibility (Agovina 2002). As in other advertisements for prescribed pharmaceutical products, viewers are urged to consult their doctors. But these ads, initiated in September 2002, are the first of their kind to promote genetic testing directly to the public and are a part
of a controversial marketing effort to expand use of Myriad's products. According to Gregory Critchfield, president of Myriad Genetic Laboratories Inc., the campaign is designed "to make these tests for mainstream." (Agovina, 2002). Yet genetic testing for hereditary cancer susceptibility was never designed for population screening. The test has applicability in a small subset of patients whose family history of cancer suggests a genetic origin. Geneticists, medical organizations and advocacy groups contend that with a relatively small real market for the BRCA1/2 test, the entire campaign is based on the push for profits (Agovina, 2002). Not only is the significance of a positive test unknown in the general population, but widespread genetic testing could cause unnecessary anxiety, increase medical costs and perhaps even create a false sense of security, with a negative result misinterpreted as meaning the person is at no risk for breast/ovarian cancer. Thus a commercial move, which lacks scientific or clinical merit, may influence how both the public and medical professionals come to understand and use the test. Similar to the patenting issue, this debate is ongoing.

Summary

This chapter is primarily a descriptive one. I described the structure of scientific and medical knowledge about genetic testing for hereditary breast/ovarian cancer. As well, through my description of the HCP, I aimed to illustrate how a research program develops in response to constructed scientific understandings and evolving medical practice. I also endeavored to show how various social, economic and political interests affect the development, implementation and particularities of a clinical and research program. Myriad’s legal action, for example, clearly demonstrates the power of a commercial enterprise to shape how susceptibility testing will be used and possibly understood.
Many of the studies on the psychological impact of genetic testing could be characterized, as Henderson (2001) so aptly puts it, a ‘fact finding mission.’ They are generated from a familiar concern that genetic information poses a potential threat to individual well-being. However, with few exceptions most studies focused on standard psychological predictors and tended to disregard the diversity of experiences that contributes to a person’s perceptions of hereditary cancer and cancer risk. These studies also failed to address the social context in which genetic testing takes place. Although small in number, qualitative studies are beginning to address these shortcomings by focusing on how people interpret and give meaning to genetic testing for hereditary cancer. Yet, to my knowledge, few studies have explicitly addressed the ethical implications of BRCA1/2 testing on people’s everyday lives. This is an important field of inquiry. Without detailed accounts of effects of genetic testing on moral agency, family relations and the social lives of tested persons, the potential harms and benefits of this technology cannot be fully assessed. In the next chapter, I discuss the theoretical literature that helped me to further conceptualize my research questions based on this gap in knowledge.
CHAPTER 3:

Surveying the Ethical Terrain

All of us depend on languages and patterns of evaluation within which we make moral judgments and explain moral life to ourselves...But distributions of social power and authority make some people’s uses and interpretations of these resources more effective than those of others. When considering what representations this medium allows, we should ask: What actual community of moral responsibility do these representations claim to represent, and whom do they actually represent?

----Margaret Urban Walker, Moral Understanding: A Feminist Study in Ethics

Introduction

The previous chapter summarized the empirical literature on genetic testing for hereditary breast/ovarian cancer. This research provides a reference point for some of the ethical issues in genetic testing: Namely, do the benefits outweigh the harms? In this chapter, I move to a more theoretical level. I examine the ethical issues raised in the contemporary bioethics literature on genetic testing for hereditary breast/ovarian cancer. I then explore the contributions feminist ethics and feminist scholarship have made to this discussion. I highlight significant issues raised by these bodies of literature, as well as identify areas of inquiry left unresolved.

This chapter is divided into four sections. Understanding ethical concerns related to genetic testing requires a broader reflection on ethical theory within health care. In the first section, I seek to locate genetic testing within this larger context of ethical discussion. Here I briefly and selectively discuss mainstream western approaches used in health care ethics (principlism, casuistry, virtue and care ethics) and their critiques. In the second section, I survey the issues that bioethicists have judged most important in evaluating predictive cancer
genetics. Foremost amongst these are issues of privacy, confidentiality and individual responsibility to the family (Dickens and Taylor 1996; Stranc and Evans 1998). Also salient to discussions of genetic testing is the potential for discrimination or social stigmatization based on genetic characteristics.

In the third section, I explore the contributions that feminist ethics and feminist scholarship make to the understanding and analysis of ethical issues in genetics. I begin by clarifying my conceptualization of feminist ethics and review the contributions it has made towards understanding concepts of autonomy, moral agency and self. I then trace four relevant issues raised by this theoretical approach: genetic individualism, genetic essentialism, genetic responsibility and the relational/embodied experience. It is possible that some of the concerns I raise from a feminist perspective, namely genetic individualism and genetic essentialism, may be raised from other theoretical positions. However, in each of these categories feminist ethics brings to bear the unique concern of power relations in structuring relevant interactions. It is also well suited to investigating the role of location, age, gender, class, and other social factors in shaping concepts and the moral implications of genetic testing. I conclude by discussing some of the issues left unresolved by both fields of inquiry.

**Mainstream approaches to bioethics**

Compatible with the metatheories of deontology and consequentialism, principlism has come to dominate biomedical and health care ethics (Pellegrino 1993; Winkler 1996; Wolf 1996b). Wolf defines principlism as:

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32 Consequentialists hold that the rightness or wrongness of an action is determined by the goodness or badness of its consequences. In emphasizing the importance of ends, it tells us that the right action is the one that produces the best outcome (best ends) for the greatest number of people. Utilitarianism is the most familiar form of consequentialism, in which consequences are assessed in terms of the total amount of happiness or welfare of persons produced by the action (Beauchamp & Childress, 1994). Other values that may guide
[A]n approach to reasoning about ethical problems that proceeds in the main not deductively, from higher-order theory, or inductively from fine-grained attention toward the situation presented, but from middle-level principles down to the case presented (1994: 400).

The ascendance of principlism in health care can be traced to Beauchamp and Childress’s (1994) influential text, Principles of Biomedical Ethics, now in its fourth edition (Wolf, 1994b). Developed to mediate between different kinds of theories, principlism does not offer a comprehensive theory, but rather affirms a conception of morality that is grounded in common values, beliefs and accepted rules of human conduct (Strong 1988; Beauchamp and Childress 1994). Central to Beauchamp and Childress’s work are four basic principles: autonomy, beneficence, nonmaleficence and justice. In health care, respect for patient autonomy is usually understood as the individual’s right to direct her/his health care based on their own values and notions of welfare (Sherwin 1998). It requires that patients are informed about possible risks, benefits and alternatives to a proposed intervention, so they can choose whether or not they wish to be treated. It requires that the decision-making capacities of autonomous persons are respected and is usually equated with informed consent (DeGrazia and Beachamp 2001). The principles of nonmaleficence and beneficence are often considered to be utilitarian principles (Winkler 1996). In medicine, these refer to the duty of seeking patient benefit through actions that are less harmful than beneficial (Burgess and Rodney in preparation). Justice is typically known as the basis from which to claim the right to health care (Burgess and Rodney, ms. in preparation). Equated with fairness, justice is based on the assertion that we ought to treat similarly all those who are similarly situated. Yet importantly,

utilitarianism are (1) the satisfactions of aims and desires and (2) attainment of conditions such as autonomy, understanding, achievement and various kinds of functioning (DeGrazia and Beauchamp, 2001). In contrast, deontological theories stress the importance of means - it is specific features of an action, rather than its consequences, that make an action right or wrong. Deontologists assert that ethics is a matter of determining which actions are required or prohibited as a matter of moral duty (Sherwin, 1992).
Beauchamp and Childress (1994) observe that justice is not a single principle. It consists of "divergent and controversial appeals" and is represented in various different theories (p. 265). A theory of distributive justice, for example, is "an attempt to establish a connection between the properties and characteristics of persons and the morally correct distribution of benefits and burdens in society" (p. 258). Distributive justice, then, refers to what is fair treatment in a society with a defined set of medical and economic resources (Burgess and Rodney, ms. in preparation).

Despite the broad acceptance of principle-oriented ethics, it's not without its critics. Those who appeal to a unifying theory fault principlism for failing to provide the level of certainty and rigor that one should expect from ethics methodology (Clouser and Gert 1990; Green 1990). For example, Clouser and Gert (1990) argue that principles are superficially related concepts and, whenever principles conflict, the decision-makers are left to their own intuitions to resolve a moral quandary. Because of the lack of "a single clear coherent and comprehensive decision procedure for arriving at answers," (p. 233), they caution that a principle-based approach provides no systematic guidance and will ultimately lead to some kind of relativism.

In contrast, others call for a much more contextualist and relational approach to ethics. They claim that principles are too abstract, too rationalistic and too removed from the everyday realities in which moral choices are actually made (Cooper 1991; Pellegrino 1993; Jonsen 1996; Winkler 1996). Cooper (1991) describes principle-orientated ethics as an "ethics of strangers" because of the detached way in which theory is applied. Principles can help identify morally relevant factors, but by themselves "ignore a person's character, life story, cultural background and gender" (Pellegrino, 1993). Others hold that principlism runs
the risk of becoming a cookbook approach to ethics, especially when it is used unreflectively (Cooper, 1991; Green, 1990). They criticize principle-based ethics as being too prescriptive and distanced from the complexities of concrete ethical situations. Further, principlism has been faulted for placing too much emphasis on the individual patient or practitioner (Sherwin 1992; Sherwin 1998). It rarely takes into consideration the social institutions which shape professional practice or delivery systems that allow some cases to surface as problems and others not. In Virginia Warren’s (1992) words, which problems we chose to study - and choose not to study - is itself a moral issue.

In more recent discussions, scholars have noted that many of the problems associated with principlism arise not so much from the principles themselves, but the uncritical manner in which they have been adopted (Sherwin 1992; Tong 1997; Sherwin 1998; Burgess and Rodney in preparation). Indeed, Beauchamp and Childress (1994) claim that although principles may be useful tools to use in sorting through an ethical dilemma, other elements are important as well. In their words: “Often what counts most in moral life is not consistent adherence of principles and rules, but reliable characters, moral good sense and emotional responsiveness. Principles and rules cannot fully encompass what occurs when parents lovingly play with and nurture their children, or when physicians and nurses provide palliative care for a dying patient” (1994:501). Nonetheless, as a result of the aforementioned challenges, alternative approaches have been developed to ethics. Here, I briefly describe three: casuistry, virtue-based theory and care ethics.

Casuistry

Casuistry is an inductive approach to ethics that largely involves case analysis (Jonsen and Toulmin 1988; Jonsen 1996; Arras 1997). Its defining feature, write Jonsen and
Toulmin, is that it uses “the concrete circumstances of actual cases, and the specific maxims that people invoke in facing actual moral dilemmas” (1988:13). It does not apply principles in prescriptive fashion, but rather attends to the particulars of individual cases. As a method, it favors a ‘bottom-up’ approach. It employs analogy “comparing this case with other similar cases, noting both similarities and differences” (Dubose and Hamel 1995). Certain cases, in which justification rests on broad grounds or principles, can be called “paradigm cases” (Jonsen 1994). Other cases, which are more complex or less clear, are “analogous cases” -- similar to the paradigm in certain ways and different in others. Casuists claim that it is the comparison of these different cases that bring situated moral problems into view and can lead to refinements in moral understanding.

According to Arras (1997), the nature of ethical principles, which are not always clear from a principle-based approach, may be informed by casuistry through its attention to particular cases. Thus casuistry is not incompatible with principles; nor does it reject them. “Its nemesis is the absolutization of principles” (Pellegrino, 1993: 1161). Yet, as Jonsen maintains, casuistry goes beyond principles for moral understanding. Moral judgment about a particular case stems from the thoughtful integration of diverse elements. As he puts it: “Moral judgment is a patterned whole into which principles, values, circumstances and consequences must be fitted. The particular judgment itself must be fitted into a larger set of judgments about moral suitability of behavior and practices” (Jonsen, 1996:45). Thus what casuistry adds to ethics is the notion that moral reasoning and justification must be sensitive not only to principles or moral rules, but to circumstances, background settings, communal practices and values that make it possible for some moral understandings to prevail (Jonsen, 1994). It sees ethics developing from a social consensus formed around particular cases,
which can then be applied to new cases. "As a history of similar cases and similar judgments mounts, a society becomes more confident in its moral judgments, and the stable elements crystallize in the form of tentative judgments about how to handle similar cases" (DeGrazia and Beauchamp, 2001: 39). Certain cases (also called paradigm cases) serve as the focal points for reflection and decision-making (Jonsen, 1994).

Like principlism, however, casuistry has not gone unchallenged. Its lack of theoretical allegiance and reinforcement of conventional social practices have been a major source of criticism (Arras, 1997). It has been criticized for focusing too much on individual cases and neglecting to attend to the broader contextual and structural issues behind the cases (Callahan 1996; Koenig 1996). Theorists have also faulted casuistry for its emphasis on how to interpret cases, without providing guidance as to which cases "make it on to the bioethical agenda" (Arras, 1997:176).

Virtue Based Theory

While it does not typically stand alone as a moral theory, there has also been a growing interest in the role of virtues in health care ethics. Rather than emphasizing rights or obligations, virtue ethics is attentive to the character of the moral agent who performs actions and makes choices (Beauchamp & Childress, 1994). In his book After Virtue, MacIntyre (1981) cites the virtues of justice, courage and honesty as being integral to the professional-patient relationship. In terms of medical practice, justice comprises fulfilling one's obligations to patients, colleagues as well as the profession and society as a whole. Courage refers to providing whatever treatments are considered best for the patient, even if one is uncertain; and honesty necessitates realizing one's limits as a health care practitioner (Tong, 1997). Virtue ethics clearly does not provide sufficient action guidelines for practice;
moreover, it must be grounded in some prior theory of what is right and wrong or judgment of what constitutes virtuous trait (Pellegrino, 1993: 1161). Nonetheless, virtue theory may be a useful construct for considering the integrity and character of the care-giver in ongoing professional-patient relationships (Burgess and Rodney, ms. in preparation).

Care Ethics

Other critics of principlism have called for an approach to ethics based on an ethics of care. Carse (1991), Cooper (1991), and Fry (1991) argue that principle-approaches to ethics reflect the sorts of rules that govern contracts among strangers. While a stranger ethic may be unavoidable or even necessary for many aspects of our lives, it fails to consider moral concerns that deal with needs and responsibilities that are characteristics of relationships (Cooper 1991).

The ethics of care, by contrast, focuses upon the moral perceptions, thoughts, feelings and emotions that arise from the actual caring for people. It builds upon some of the tenets of virtue ethics by maintaining that good persons are not only honest, courageous and just but also caring (Tong, 1997). In particular, it places emphasis on traditional female virtues such as empathy, sympathy, compassion, nurturance and love (Bowden 1997). It supports an ethics of personal relations by giving recognition to the desires and responsibilities of individuals in situations of interdependency, vulnerability and trust (Gilligan 1982; Noddings 1984; Carse 1991; Held 1993; Baier 1995). Contrary to traditional theory, an ethics of care also values the importance of emotion in ethical reasoning. Sensitivity to other people, that is "a capacity to perceive (as best we can) how others feel," (Carse 1991:12) is considered essential to informing our understanding of the needs of others. Emotion is also thought to be integral to the manner in which one responds, and how actions are performed. As Brody
(1994) writes, “a kind of compassionate act is an act which is carried out in a certain emotional state” (p. 212).

Like the previous ethical approaches, however, care ethics has been criticized on a number of fronts. Critics point out that an ethics of care gives little direction at the macro level of health care because of its individualistic and relational basis (Nelson 1992). Others recognize that its lack of theoretical or conceptual underpinnings may leave decision-making open to capriciousness and arbitrariness (Fry, Killen et al. 1997). Still others allege that an ethics of care may reinforce situations or traits that are oppressive to women; specifically, because of links to mothering, there is the danger that caring will come to be seen as an innate characteristic of women, and a determinant of women’s social roles and possibilities (Hoagland 1991; Sherwin 1992; Bowden 1997). Baier (1986) suggests that untempered care, like undiscriminating trust, can lead to exploitation especially when there is no reciprocity. Thus, while care ethics holds promise as an adjunct to principles, its articulation needs further development if it is to resist a model of caring that has been built under oppressive conditions (Bowden, 1997).

This section has provided a brief overview of the mainstream philosophical approaches to health care ethics. I now turn to an examination of the mainstream bioethics literature concerning ethical problems raised by genetic screening for hereditary breast/ovarian cancer.

**Genetic testing for hereditary cancer: Ethical considerations**

Despite questions of cost (and who will pay), susceptibility testing for hereditary breast/ovarian cancer has generated considerable interest. The promise of earlier disease detection, more effective treatment or the potential for preventative action is alluring.
Nonetheless, numerous organizations, health care professionals as well as lay critics have voiced concern that people may be harmed by information generated from DNA testing. Cited most often, as key ethical issues, are privacy, confidentiality and the threat of genetic discrimination [Burgess, 1999 #47; (Knoppers 1998).

In his paper, “Privacy and the Right to Privacy,” McCloskey (1980) identified ten opinions characterizing privacy. Of particular relevance to genetic testing is the definition of privacy “as the lack of disclosure, and the right to privacy as the right to selective disclosure” (p. 22). Here, privacy refers to the degree of control that we have or can maintain over what others know about us (Stranc and Evans 1998). It refers to an individual’s authority to reveal or withhold information that is about her, in this case, to direct who may or may not have access to presymptomatic information. Others stress that privacy is important, not just because of its legal implications, but because of its role in establishing moral personhood. Reiman writes: “Privacy is a social ritual by means of which an individual’s moral title to his existence is conferred...the right to the existence of a social practice which makes it possible for me to think of this existence as mine...the right to privacy, then, protects the individual’s interest in becoming, being and remaining a person” (Reiman cited in Jonsen, 1994:283). According to Reiman, then, privacy is central to establishing personal boundaries. It shapes the way we view who we are as individuals, as well as the way in which we see others viewing us. Writing on ethical conduct for research involving humans, McDonald and colleagues state that privacy is a critical feature of personal relations. They put it this way:

Privacy is valued not only because certain information is felt to be embarrassing, shameful or in other ways hurtful to the participant, but also because privacy is essential for intimate, personal and even spiritual relationships, that is, with what is thought to be “sacred in a variety of ways” (July 1997 Report of the Tri-Council Working group: 111-1).
Thus, privacy is a concept closely connected to constructions of self, identity and personal autonomy.\textsuperscript{33} It is also a central concept with respect to genetic testing.

As with any medical test, individuals are encouraged to exercise personal autonomy in deciding whether or not they wish to pursue genetic testing. From a clinical standpoint, autonomy is supported through standardized protocols that emphasize genetic counselling and informed consent (Burgess, Knoppers et al. 1999; Burgess and d'Agincourt-Canning 2001). In pre-test counselling, individuals discuss with genetic counsellors the possible benefits and potential harms of receiving genetic information. Patients must evaluate whether the risks are worth taking based on their own values and notions of welfare. Similarly, people’s entitlement to privacy ensures that they are seen as knowing best with whom, when, and how to share this information.

Scholars point out, however, at odds with traditional notions of autonomy and privacy is the fact that predictive testing has serious implications for others. Genetic information is personal, but at the same time, familial (Knoppers and Godard 1998; Henderson 2001). Because of shared DNA, one person’s susceptibility to a genetic disease means that other biological relatives will also be at risk of developing the same disease. Thus, the interests of one family member cannot be entirely separated from the interests of others (Sommerville and English 1999). An individual’s knowledge of being a carrier of a genetic mutation blurs the traditional boundaries of personal autonomy (Lemmens and Bahamin 1998). Predictive testing for breast cancer reveals information about the tested individual, as well as the future health of her children, siblings and extended family.

\textsuperscript{33}Philosophers have long struggled with the concept of autonomy. But for the purposes of this paper, I adhere to a basic definition in which autonomy is taken to mean self-determination or self-governance, that is the right to choose and pursue one’s own plan of life and action (Friedman, 1997; Sherwin, 1998). In medicine, respect for patient autonomy is the ethical basis of respect for privacy (July 1997 Report of the Tri-Council Working Group) as well as informed consent (Sherwin, 1998).
Although genetic testing does not create substantively new dilemmas about patient confidentiality, problems may arise if an individual refuses to share information, which the clinician or other family members believe that she should share with them (Sommerville and English, 1999). Confidentiality is considered a hallmark of the clinician-patient relationship. Yet, as Sommerville and English (1999), Henderson (2001) and others point out, ethical tensions may arise regarding who should or should not have access to genetic test results, especially if clinicians perceive this information as relevant to health care decisions faced by others. The problem becomes particularly salient if a genetic disorder or condition is thought to be preventable and a genetically at-risk individual chooses not to disclose information she possesses. In such situations, clinicians may find themselves torn between competing duties: the duty of confidentiality and the duty to protect others from potential harm (Roy and Dickens 1994; Dickens and Taylor 1996; Stranc and Evans 1998).

Currently in Canada, the speculative nature of the benefits is inadequate to justify a legal duty to warn relatives that they may have inherited an increased risk for breast/ovarian cancer (Burgess, Knoppers and Laberge, 1999; Knoppers and Godard, 1998; Dickens et al., 1996). However, legal commentators caution this may change if more effective interventions are developed, and there is evidence that disclosure of genetic information could prevent harm (Burgess, Knoppers and Laberge, 1999; Dickens et al., 1996; Knoppers and Godard, 1998). Similarly, bioethicists have examined the moral nature of this dilemma and many have taken the position that genetic privacy is not absolute. Jonsen (1994), for example, argues that it is important to consider questions of privacy with the context of duties and responsibility to one's biological family. He asserts that an individual who has genetic information about herself has a moral obligation to share that information with others within

34 See the American Journal of Bioethics (2001), Volume 1, number 3, for an extensive discussion of this topic.
the kinship. Although he recognizes this duty is complicated by the type of illness, its severity and the probability of harm involved (and thus should be evaluated on a case by case basis), he maintains that the paradigm for genomic privacy is kinship. In his words:

An individual who has genomic information about himself or herself has an obligation to share that information with others who have a relevantly similar genome, those within his or her kinship. The justification for this obligation is that the information is not his or hers but theirs; they all inherit the similar genome and information derived from it affects their lives. The information contributes to their exercise of moral responsibility as persons. The realm of privacy, therefore, does not stop at the individual but includes all within the kinship....since the information properly speaking belongs to the kinship (Jonsen 1994: 289-290).

In a more recent article, Sommerville and English (1999) reach a similar conclusion. They argue that persons diagnosed with a genetic disorder have a moral duty to share that information not only with relatives, but also with spouses and partners with whom they may have children. Calling for a more communitarian approach to ethics, they maintain the view that individualistic notions of autonomy are insufficient to deal with the complexities arising from genetic testing.

A more useful framework is gained by combining notions of autonomy with a modified version of communitarianism which recognizes that decisions made by one individual inevitably affect others and that an individual cannot have rights without also accepting that he or she has certain duties...In the genetic sphere, for example, hard questions arise about the moral acceptability of the individual’s usual right to privacy. (p. 150).35

35Those who favor a communitarian approach assert that ethics is not a matter of individual rights, but a project achieved within community. Emphasis is placed on dialogue that allows for honest discussion and values social responsibility (communal benefit) over individual rights (Beauchamp and Childress, 1994; Tong, 1997). Among the philosophers who favor this ethical approach are Charles Taylor, Michael Sandel and Alasdair MacIntyre.

36 Disregarded in this approach are considerations of the nature or quality of particular relationships. I explore this more deeply in the section on feminist ethics. Also, disregarded in this approach are considerations of reciprocity. For instance, will family members with whom an individual is obligated to share genetic information feel an equal obligation not to tell third parties, especially those who may use it to the individual’s disadvantage? I thank Dr. Michael Mcdonald for bringing this latter point to my attention.
In addition to the need to reconsider traditional notions of privacy, however, are equally problematic issues regarding discrimination. Critics warn that employers, insurance agencies, schools, government agencies and others, for various reasons, will want access to genetic information (Roy and Dickens 1994; Nelkin and Lindee 1995; Dickens 1998; Cox 1999). Without appropriate safeguards in place, genetic information may be used as an exclusionary tool (Rowin 1988). Persons may be denied social opportunities and benefits based on genetic “difference” (Lemmens and Bahamin 1998; Sorbonne 2001). Avenues may be closed to individuals because of their genetic status rather than physical condition. Further, others caution that the threat of discrimination may hinder people from seeking the benefits of some genetic tests (Ball, Ondrusek et al. 1998).

Most risks associated with genetic testing potentially have to do with the use and potential abuse of personal information by third parties. Although cases of exclusion are anecdotal, some studies indicate that genetic testing has been used to bar people diagnosed with a genetic disorder from insurance coverage and employment (Lemmens and Bahamin, 1998; Nelkin and Lindee, 1995). Others warn that genetic knowledge may lead to reduced tolerance for diversity and, if unregulated, heighten inequities by labeling groups with particular genetic diseases or risks (Markel 1992). Ethnic or racial issues may further augment the risk of stigmatization. Thus, a potential for genetic discrimination may be accompanied by a potential for “genetic elitism” (Dickens 1998: 110).

Concerned about the potential misuse of genetic information, governments worldwide debate the nature of new legislation needed to ensure that DNA testing is used in appropriate ways (Knoppers and Godard 1998; McGleenan and Weising 1999). In the USA, a NIH-DOE task force on genetic information and insurance clearly stated that genetic information should
not be used to deny health care coverage or services to anyone (1993). It also recommended that until universal access to health coverage is made available, insurers should contemplate a moratorium on genetic testing in underwriting (Knoppers and Godard, 1998). In Canada, a study paper for the Law Reform Commission of Canada as well as the Science Council of Canada, issued similar recommendations. They recommended that a guaranteed, basic form of life insurance be made universally available, with additional insurance optional and subject to genetic information supplied by the applicant (Knoppers 1991; Science Council of Canada 1992).

Clearly, insurance companies, employers and multiple others hope to gain financially from knowledge of people’s susceptibility to inherited cancer. While classical legal principles and human rights legislation afford broad protection to human rights, it is widely recognized that genetic testing will necessitate further legislation against social harms (Knoppers 1998; Knoppers and Godard, 1996; Lemmens and Bahamin, 1998). A recent newspaper article reported that the Federal Health Minister, Anne McLellan, is consulting with provincial and territorial counterparts on the feasibility of establishing a national initiative to balance the interests of employers and insurance companies against the “legitimate privacy considerations of Canadians” (Staples 2002). Ethical analysis and human rights legislation also needs to consider whether genetic technology contributes to the oppression, either subtle or overt, of certain groups. Yet, while theorists have warned that discrimination against vulnerable groups is a possible danger of genetic testing, gender has been largely overlooked in mainstream analyses. This is surprising given that genetic testing

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37 For a summary of concerns regarding genetic testing of vulnerable groups see Burgess and Brunger (2000); Knoppers and Godard (1998) and Jonsen (1994).
for BRCA1/2 mutations affects women far more than men. Feminist work offers to contribute much to ethical analysis here.

**Feminist ethics**

Due to the fact that there is more than one kind of "feminist ethic," I will begin by clarifying how I use the term. Feminism is "the name given to the various theories that help reveal the multiple, gender-specific patterns of harm that constitute women's oppression" (Sherwin, 1992: 13). Although there exists a plurality of feminist approaches, methods and epistemologies, it is probably safe to say that most feminist work takes gender and the "power relations that structure gender relations" (Sherwin, 1992: 19) as important analytic categories. The fact that feminists approach social problems using different theoretical lenses explains why feminist ethics exists in the plural.\(^\text{38}\) (Tong, 1997).

According to Sherwin (1992), Sichel (1991), Tong (1997) and others, one way to categorize the vast array of feminist approaches to ethics is to distinguish between "feminine" versus "feminist" ethics. As Sichel (1991) explains, feminine approaches to ethics emphasize women's experiences, practices and moral points of view. This entails a notion of ethics that is attentive to women's moral reasoning and is anchored, in the most general sense, by the concept or ethic of care. It has as its primary task the recognition of culturally associated feminine values such as compassion, empathy, sympathy, nurturance, kindness and care (Tong, 1997). It aims to address the exclusion of women's lives in moral theory by delineating understandings of value, agency and responsibility in women's lives (Walker, 1998).

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\(^{38}\)Tong (1997) has classified the range of feminist approaches to ethics as liberal feminism, Marxist feminism, radical feminism, postmodern feminism, psychoanalytic feminism, socialist feminism and existential feminism.
In contrast, "feminist" ethics explores the workings of gender and power in society (Wolf 1996b). While attentive to context, it goes beyond the recognition of the experiences and moral practices of women, to a "critique of the specific practices that constitute their oppression" (Sherwin, 1992: 49). It makes visible the various ways in which people's interpersonal relationships are shaped by larger social patterns; and promotes awareness that "power attaches to people as members of social groups and not merely as a consequence of their own efforts in the world" (Baylis, Downie et al. 1998: 235). Because we live in a world structured by hierarchy, feminist ethics urges us to examine how moral experience is shaped, acted upon and even constrained by social roles and positions. It poses questions about whether institutions and practices perpetuate oppression by serving the interests of one group over another. It holds the view that oppression is an intolerable form of injustice and therefore morally wrong (Sherwin 1992b). Accordingly, feminist ethics insists that questions about oppression must be added to ethics evaluations of health care practices. A further goal of feminist ethics is to pursue changes necessary to end oppression (Sherwin, 1992, 1998; Tong, 1997).

Although differences exist between feminine and feminist ethics, most theorists recognize there is overlap between the two. Feminist ethics, in practice, is about describing and analyzing women's moral experience, while rooted in a sensitivity to contexts of domination. It involves a tacking back and forth between the contextualized moral experiences of women and the political inscription of women. It begins with the insistence, as

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39 Gore's work (1993) on feminist pedagogy has helped me to think through this distinction. Although an over simplification, I look at the difference between feminine and feminist ethics as one which places emphasis on ethics and the other on feminism. Put another way, one group writes about feminist ethics from the context of women's experiences. Here the emphasis is on the diversity of female values that comprise women's understandings of ethics, that is, what is feminist ethics? The other group writes from the context of power relations and asks what makes ethics feminist?
Wolf (1996) remarks, that analysis starts with attention to the concrete and the particular. At the same time, it demands that attention be paid to the effects of social arrangements on moral understandings and experiences. Questions of morality, like those of epistemology, involve issues of power (Smiley 1992; Walker 1998).

While the first goal of feminism is to work towards the identification and eradication of oppression, feminist ethicists have also challenged the adequacy of certain ethical principles. As stated earlier, autonomy is a key ethical principal in evaluating many issues in health care, including the pros and cons of genetic testing and the purposes of genetic counselling. Yet, many feminist scholars view the traditional concept of autonomy as lacking. Autonomy as it is used in nonfeminist ethics stands as a principle of self-governance or self-determination. It is viewed as “the instrument of agency for individuals who are perceived as separate, independent and fully rational” (Sherwin, 1992: 137). It is allied with liberal theories of abstract individualism. According to Sherwin (1998), Friedman (2000), Barclay (2000) and others this focus on rationality and self-interest is objectionable because it neglects the relational, contextual nature of autonomy. It fails to consider that people are not independent, nor does their decision-making always meet the norms that define rationality. It ignores the social nature of the self and the importance of social relationships to the projects and attributes of self (Smiley 1992; Friedman 1997; Walker 1998; Friedman 2000).40

40 This work parallels earlier theories developed by sociologists known as symbolic interactionists. George Mead (1934) and Herbert Blumer (1969) are among those best known for this work. Mead (1934) asserted that each person has a self, and this self is only possible through interaction with others. As people interact they create new meanings for things in their lives and through reflection, who they are in society (Blumer, 1969). According to Mead and Blumer, social life is the foundation for consciousness and emergence of self; there can be no self without interaction. These themes are echoed in feminist arguments about the importance of social relationship to attributes of self. I thank Elvi Whittaker for bringing this literature to my attention.
Many feminist theorists (Keller 1985; Hoagland 1988; Nedelsky 1989; Code 1991; Held 1993; Friedman 1997; Meyers 1997) call for a more contextual approach to autonomy, which integrates notions of interdependence, solidarity and community. The term ‘relational autonomy’ has been adopted to portray the concept that social relationships are central to the realization of autonomy (Friedman, 1997). Like other theoretical positions, relational autonomy is not a monolithic term but encompasses a range of perspectives (MacKenzie and Stoljar 2000). The common thread, however, is the conviction that persons are socially embedded and that an individual’s identity is formed within the “context of social relationships and is shaped by a complex of intersecting social determinants, such as race, class, gender and ethnicity” (MacKenzie and Stoljar, 2000: 4). In other words, a social component is built into the meaning of autonomy (Nedelsky, 1989: 35-36). It is part of what autonomy actually is. Donchin (2000), who also favors a relational approach to autonomy, calls attention to the fact not all relationships are voluntary. She argues for a ‘strong’ model of relational autonomy that requires collaboration, long-term reciprocity and an equitable balancing of power relations. Likewise Sherwin (1998) emphasizes the need for an expanded definition of relational autonomy that takes into account the importance of social, material and political conditions in structuring self and autonomy (Sherwin, 1998). Thus, the focus of relational approaches is to explore the implications of subjective, intersubjective and social dimensions of selfhood in relation to moral and political conceptions of autonomy (MacKenzie and Stoljar, 2000). Its aim is not to reject the notion of autonomy, but broaden it with a relational concept that recognizes persons are in fact “second persons,” who only become persons in relation to others.

41 Annette Baier (1985) introduced this notion of second persons in her book, Postures of the Mind: Essays on Mind and Morals. She wrote “Persons are essentially successors, heirs to other persons who formed and cared
Some of the theoretical challenges feminist scholars have raised about autonomy also apply to moral agency and philosophical understandings of selfhood. Sherwin (1998, 1992) has critiqued traditional concepts of moral agency in which the latter is typically seen as the capacity to choose and pursue individual goals. Traditionally, characteristics that have defined agency include rationally, autonomy and self-interest (Sherwin, 1992). Yet, Sherwin, Held (1993) and some communitarian philosophers argue this abstract concept is largely blind to the everyday relational and contextual nature of people’s lives. It overlooks the fact that the capacity to choose depends on the actual position and relations of people in a particular social order (Walker, 1998). As Walker remarks: “This social order is the kind where the availability of these positions depends on gender, age, economic status, race and other factors that distribute powers and forms of recognition differentially and hierarchically” (1998: 22). Our latitude for choice is affected by the multiple kinds of relationships that exist within society, many of which are characterized by an imbalance in power (Sherwin, 1992). Once again, feminists do not totally reject rationality, autonomy and self-interest as characteristics of moral agency but call upon us to broaden our perspective.

Feminist theorists have applied these theoretical concepts to practical situations as well. In health care, for example, Lock (1998), Morgan (1998), Mitchinson (1998), Rodney (1997) and Sherwin (1998) argue that we need to rethink the traditional model of decision-making where treatment decisions are approached as if they are simply an individual matter between patients and physicians. This concept denies the complexity of choice and the fact that no one single factor will be the sole influence on decision-making. Moreover, as Sherwin (1996, 1998) points out, traditional models tend to obscure the fact that by the time particular

for them, and their personality is revealed both in their relations to others and in their response to their own recognized genesis” (p.85). MacKenzie and Stoljar (2000) describe this as a critique of autonomy on metaphysical grounds; human beings are constituted, not simply shaped, by relations to others.
treatment decisions have to be made, treatment options have been limited by political and policy decisions that have occurred within the large institutions of health care. The set of options made available to patients (and physicians) reflect a series of earlier and complex decisions regarding research agendas, the allocation of economic and health care resources and the funding policies of government and third-party payers (Sherwin, 1996: 192). The explicitly political orientation of feminism demands that this prior layer of decision-making is made transparent and assessed.

Feminist ethics and susceptibility testing

Given this brief description of feminist ethics, I would now like to tackle the question: what kinds of contribution can feminist scholarship make to the understanding and analysis of ethical issues in genetic testing for breast cancer? As previously stated, genetic testing is seen as a technology that will assist individual decision-making as well as promote individual welfare. Seen from this vantage point, informing persons about the benefits and harms of genetic testing not only protects their rights as autonomous decision-makers, but empowers them to exercise personal control over their lives. Indeed, genetic testing may be viewed as a technology that can inform medical and personal life decisions. It offers information that, according to a European report on ethical and philosophical issues of genetic screening, “will facilitate autonomy” (Chadwick and Levitt 1996: 67).

Feminist ethicists also appeal to the principle of autonomy when examining the implications of genetic testing for breast cancer. Like other proponents of the technology, many recognize that women will want this information to make decisions about their lives (Asch and Geller, 1996). Indeed, for some women with strong family histories of breast cancer, knowledge about genetic risk may enable them to make careful, informed choices
and to exert control over a disease that has created a sense of powerlessness and fear in their lives. Thus, feminist ethics, like principlism and other ethical approaches, reflects an interest in equal access to genetic testing and the freedom to choose such technology. However, from a feminist perspective, autonomy cannot be understood without considering power relations that structure relevant interactions. A feminist analysis directs attention to how genetic testing and questions of choice fit into a broader framework of social practices and policies. It asks us to examine the specific circumstances of people involved in testing, to take into account their actual experiences and concerns and to assess the significance of genetic testing on personal and social relationships. When looked at in this way, feminist ethics targets additional areas for evaluation and concern. These can be divided into four broad areas of inquiry: genetic individualism, genetic essentialism, genetic responsibility and the relational/embodied experience of genetic testing. The first three categories address general concerns about all forms of genetic testing, including BRCA 1/2 testing, while the last one applies more specifically to the breast/ovarian cancer experience.  

**Genetic Individualism**

Despite recognizing its potential benefits, feminists worry that one of the consequences of genetic testing may be excessive individualism (Asch and Geller 1996; Sherwin 1996). Just as mammography is presented as a means of saving lives, genetic testing promotes the view that women can impact their cancer mortality if they know their genetic status. In doing so, genetic testing places a high degree of emphasis on individual

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42 Some of these issues have been discussed in the broader ethics literature. However, from my readings it appears that feminist theorists are the ones who have taken the lead in posing these critiques. As well, they expand the dialogue by asking sharp questions about the role of power relations in structuring relevant interactions.
responsibility for maintaining health. It positions the individual as the locus for change by treating genetic predisposition as an individual problem (Lippman 1998).

The emphasis on individual responsibility, however, reflects an assumption about 'self' that is culturally located. It purports a vision of the self as rational, unified and consciously making decisions about one's behavior and conduct. The self privileged and normalized in such discourses "is that of the enterprising and entrepreneurial self, the individual who is interested and willing to take action to improve his or her health status. It is assumed that all individuals have the potential for social action in the name of good health," (Lupton, 1995: 61). The ideology that informs genetic testing, like other approaches to health care, is strongly individualistic. It emphasizes such values as individual rights, individual choice and responsibility. It adheres to the premise that individuals have the ability to direct their lives according to personal values. Implicit here is a view of persons as autonomous: a single, individual decision maker in control of one's choices. This self is expected to live life in a sensible way, and to be ever attentive to risk (Lupton 1995).

In the face of such discourse, many express concern that the way we apply genetic knowledge can be misleading. Asch and Geller (1996) argue that to individualize genetic susceptibility, for example, ignores the variability and complexity of genetic operations. As previously stated, genes predisposing to breast cancer are not fully penetrant, meaning that not everyone who has a BRCA1 or BRCA2 mutation will get breast cancer. Yet, current knowledge "makes it impossible to determine whether those who follow recommendations and do not become ill stay healthy because they are behaving well or because their genes are not really 'risky' after all" (Lippman, 1998: 72). By focusing on the individual, genetic testing promotes the tendency to attach blame to non-action or a refusal to act. Women, who
are known to carry a genetic mutation but do not engage in surveillance practices or lifestyle modification, for example, are likely to be seen as irresponsible. With the diagnosis of individuals as its primary focus, genetic technology promotes the view that if someone does not act on this information and gets the disease, it's her own fault. Women may discover they have little community or practical support to deal with problems that society believes should be resolved through individual action (Asch and Geller, 1996).

For Sherwin (1996), the individualized focus of genetic testing is especially problematic given society's abdication of responsibility for dealing with social or environmental factors, which can trigger disease. Despite the links made between cancer and the environment (i.e. toxic chemicals, radiation, synthetic hormones, and iatrogenic substances) society has paid little attention to these factors. To the degree that the latter conflicts with economic priorities, she argues that the decision to put resources into genetic and other individually-based prevention strategies is a political decision about health policy. It protects those institutions that threaten health -- and contribute to cancer rates -- through pollution, suboptimal workplace conditions or the manufacture of harmful products. It avoids the necessity of governments having to spend money to clean up carcinogenic environments, or to institute broad social and political actions that are also integral to cancer prevention. She argues there are ethical questions to be raised about why "certain choices have been made and who has the ability to influence those priorities" (Sherwin, 1996: 199). Sherwin does not object to genetic research per se, but rather the tendency to view genetics as the primary source of this disease. She sees this view as overly simplistic, neglecting complex interactions of genes with other facets of human biology and society.
For Sherwin, the moral issues surrounding individualism extend further. Making an association between environmental conditions and the triggering of a susceptible genotype presupposes that an individual can act on that information. It completely ignores the fact that the ability to choose a healthy lifestyle, to improve diet, to avoid workplace hazards or change one’s environment is related closely to an individual’s social and class privilege (Sherwin, 1996). It fails to consider that many people are exploited, responsible for the care of others, or due to disability, finances, or location may be prevented from choosing or taking responsibility for their health. According to Sherwin, full autonomy “requires removal of the barriers of oppression that often structure options in ways that further perpetuate existing patterns of oppression” (1998:13). Yet, limitations of social location impose constraints on what people can realistically do. To speak meaningfully about choice requires that we examine the forces that both support it and detract from it.

Genetic Essentialism

Closely related to genetic individualism is another area of concern for feminist theorists: that of genetic essentialism. Nelkin and Lindee (1995) define genetic essentialism as a perspective, which “reduces the self to a molecular entity, equating human beings, in all their social, historical and moral complexity with their genes,” (p. 2). Genetic essentialism is based on the premise that biology constitutes a tangible reality, independent of history and culture. Using the metaphor of blueprints, with DNA presented as a set of instructions, it promotes the view that individual differences, behaviors, disorders and illnesses are genetic in origin. It reduces health problems to the individual and situates individuals increasingly according to the pattern of their genes. For feminist theorists, the danger of this perspective lies not only in the particular consequences for individuals, but also in more general ways of
changing our perceptions of health and disease (Nelkin and Lindee, 1995; Sherwin 1996; Lippman 1998).

Asch and Geller (1996) suggest that feminist analysis of the relationship between sex and gender is a useful model for understanding the relationship between genes and genetic essentialism. Drawing on the work of a number of feminist theorists, they assert that gender is socially constructed category, which makes assumptions based on biology. Gender refers to the social characteristics of sex, whereby men and women adopt specific patterns of behavior according to social expectations and customs. It is a process through which we are shaped and by which we shape ourselves in accordance to social or cultural norms. Gender involves behavioral and task differentiation, but it is also about power relations that shape gender roles in any one society (Stacey 1996). It has been used historically to treat women as "the other," that is different from and less than men. Wendell (1996) explains the consequences of being 'other' further.

When we make people 'other,' we group them together as the objects of our experience instead of regarding them as fellow subjects of experience with whom we might identify. If you are "other" to me, I see you primarily as symbolic of something else--usually, but not always, something I reject and fear and that I project onto you. We can all do this to each other, but very often the process is not symmetrical, because one group of people may have more power to call itself the paradigm of humanity and to make the world suit its own needs and validate its own experience (p. 74).

Indeed, this position of 'other' has had grievous impact on thinking about women's lives and capacities. As Asch and Geller (1996) so aptly observe:

To be treated as "the other" is to be denied the range of opportunities open to those in the group of valued people, and instead to be categorized and marginalized based on one personal characteristic-gender (p. 328).

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Much like the social construction of gender, feminist theorists express concern that genetic essentialism may contribute to the ‘othering’ of certain people. Genetic essentialism is deeply ideological, yet it has the potential to establish social categories based on reductionist views about genes and health (Frankin 1993). Lippman (1998) is among those who sees genetics as contributing to the erroneous belief that differences among people are best understood as biological in origin. She cautions that, “assumptions about the role of genetics in explaining these differences can only reinforce the view that they are somehow “natural” (p. 65). Disorders thought to be genetic will be seen as unavoidable or inevitable; that biology is destiny. Lippman sees geneticization as particularly problematic because not only is it misleading, but it may also eradicate a commitment to seeking a range of solutions to human problems. In conveying a message of fatalism, it may divert attention away from the broad social, environmental and political factors that contribute to cancer and other diseases. It absolves society of the responsibility of addressing the social aspects of disease (Kegley 1998).

Feminist scholars also fear that genetic essentialism will lead to the construction of new categories of illness. Indeed, Kenen (1994) speculates that mutations carriers will come to be seen as “the potentially sick, potentially vulnerable and potentially stigmatized” (p. 49). She writes that the potentially sick and vulnerable are created when diagnostic techniques can predict the probability of future disease, for which there is no prevention. Women who have inherited a BRCA1/2 mutation, for example, may be categorized as those who are not yet sick but not quite healthy. Genetic testing may turn women into patients, even though it may be years before the disease appear. The potentially stigmatized are created when the information is used to categorize people as different. Because difference is rarely viewed as
neutral, feminists urge that we remain alert to changing notions of normality. Much like discourses on sex and gender, there is a concern that mutation carriers may be defined as the unhealthy ‘other.’ At the same time as creating the newly sick, however, genetic testing does little to help the vast majority of women who get cancer (Lippman, 1998: Sherwin, 1996).

Like principlists and others who are concerned about genetic discrimination, feminists caution that genetic testing may provide the foundation for devaluing certain groups. As Lippman (1998) points out, the prevalence of genetic disorders can further stigmatize a group already affected by sexual, racial or ethnic discrimination. Not long ago, African-Americans suffered stigmatization and exclusion from health and life insurance and from employment, because they, though not sick or disabled, were carriers for the gene for sickle cell anemia. The insult of racial discrimination was added to that of genetic discrimination, understood as such because the discrimination was often only directed against African-American sickle-cell carriers, even though people from other ethnic groups can also carry this trait (Markel, 1992, p. 213). Given the fact that the Ashkenazi Jews are known to be at somewhat higher risk for carrying BRCA1/2 mutations, it is imperative that we consider if this ethnic group or others are put at risk of double discrimination.

Whose Responsibility?

As previously mentioned, genetic testing for hereditary disease often begets discussions of responsibility. Yet, conceptions of responsibility are influenced by social meanings and practices (Walker, 1998). Responsibility for family health, for example, falls disproportionately to women in our society. Scholars have consistently shown that women bear responsibility for maintaining the health of children and partners; as well, they negotiate professional health care for their families and communicate health information on their
behalf (Graham 1985; Anderson and Elfert 1989; Stacey 1996). Similarly, with regard to genetic illness, geneticist Peter Harper (1996) has observed, “for the most part, it is the women who form the central focus of the family-based problems that genetic diseases create” (p. 54).

Sociologist Nina Hallowell (1999) argues that one of the outcomes of predictive testing is that women may begin to be burdened by a sense of ‘genetic responsibility’ towards others. Because genetic testing provides information about risks to the family, she posits that feelings of genetic responsibility could limit choices, particularly an individual’s right not to know about their own genetic risks. Indeed, in an empirical study, Hallowell (1999) found that women who attended a genetics clinic for breast/ovarian cancer perceived themselves as having a responsibility to their family (past, present as well as future) to determine their genetic risks. Responsibility lay in managing their own health risks as well as in providing genetic risk information to other kin. Hallowell cautioned that choice regarding testing may be constrained by gendered discourses “which position women responsible for the care of others, for they regard their ability to fulfill their obligations of care as dependent upon taking steps to control their risk.” For women, then, the social cost of not learning one’s genetic status may be particularly high. When couched in the language of responsibility, women may relinquish their rights to not know about their genetic risk. Thus, one must ask whether the availability of such knowledge may serve to limit some women’s choices? Do men express similar notions of responsibility with respect to hereditary diseases that affect them?

Further, how individuals raise the question of genetic testing and cancer with family members, while trying to respect their privacy, is fraught with difficulty. Yet, as previously
mentioned, several recent critiques suggest that persons with a genetic disorder have a moral duty to disclose that information to other family members (Jonsen 1994; Rhodes 1998; Sommerville and English 1999). A feminist analysis might also pause to ask: does there always exist a moral obligation to inform close relatives of genetic test results? Ethical arguments about the duty to disclose are based on the assumption that knowledge about genetic risk is beneficial: that, indeed, it is better to know than to not know. A problem with this approach is that it does not take into account the social locations or life circumstances of various individuals. It fails to ask whether it serves the best interests of everyone to be informed about their genetic risk status. A person who draws on certain experiences and acts from a sense of relationship or responsibility to others, for example, might ascertain that it is better for a particular family member not to know this information; that it could, in fact, impart harm to her/him. If this person then chooses to withhold the results of a genetic test, has s/he then failed to fulfill their moral duty to others? Similarly, should the responsibility to share genetic information override prior conflict or ruptures in family relationships? In some cases, could not re-contact or communication based on the disclosure of genetic information be harmful? Does physical risk (implying a relative’s right to know) always overshadow any other kind of risk (i.e. emotional or psychological risk caused by having to share genetic results with a relative with whom one had a history of distressing or harmful interactions)?

In emphasizing the duty to reveal genetic information, most ethical analyses appear to be based on relationships between kin who are faceless and interchangeable. A feminist ethic would require more: that we start from the experience of particular individuals. At the
same time, it would remain attentive to the query: is it ever right to withhold such information from others?

**Relational/embodied experience**

Although feminist ethicists raise questions about the wider ramifications of genetic testing, their arguments are not meant to persuade women to forego testing nor minimize the complexity of women's responses to this technology. Indeed, it is clearly recognized that some women will use genetic testing to make careful, informed choices about their lives (Asch and Geller, 1996). Many women from families experiencing multiple cases of cancer view genetic testing, and the information gained from it, may be seen as empowering. Based on the recognition that "choice" does not occur in isolation, however, a feminist approach would emphasize the need to assess genetic testing in terms of personal and family relations. It would direct us to examine concerns and issues shaping women's decisions to be tested, as well as how testing shapes and is shaped by relationships with others. Recognizing that women's lives are inextricably intertwined with others, it would ask what might be the implications of this knowledge for interconnectedness and the meaning of child-parent, partner, sibling, as well as friendship relationships (Asch and Geller, 1996)? These issues by themselves are not unique to feminist ethics. Indeed, through their attention to particularities, casuistry and ethics of care would also be concerned with how genetic testing impacts personal relationships. But feminist ethics would also ask whether differences in power relations among family members or gendered structures of authority might shape or impact decisions made.

A feminist analysis of genetic testing would also explore the embodied experience of genetic testing. Although recognized, little discussion has been paid to the fact that the results
of genetic testing are mediated through a woman's body. Women are usually the ones to undergo genetic testing; they are also the ones who will partake in active surveillance or have prophylactic surgery if found to be mutation carriers. There is little doubt that the practice of genetic testing will result in ever-increasing medical involvement in women's lives. Research in this area is desperately needed.

Summary

This chapter provided a brief review of various approaches to bioethics and a survey of ethical issues raised by genetic testing for breast/ovarian cancer susceptibility. It also posed the question: what contributions can feminist scholarship make to the understanding and analysis of ethical issues in genetics? Feminist ethics is not a substitute for traditional ethics; indeed, theoretically I see an overlap between feminist ethics, casuistry and care ethics. Each of these approaches urges us to examine the specific circumstances of people involved in testing and to take into account the actual experiences and concerns of women involved in testing. Further, feminists share with principlists (and undoubtedly other theorists) concerns about privacy, confidentiality and discrimination.

However, feminist ethics has pushed the boundaries of ethical evaluation further by identifying gender, power relations and oppression as significant considerations when examining genetic testing. In doing so, it makes visible additional areas for evaluation. These include (i) genetic individualism, (ii) genetic essentialism, (iii) genetic responsibility and (iv) the relational/embodied experience of genetic testing. Although cognizant of the benefits of genetic testing, feminist theorists question whether the ideologic framework of genetic testing may lead to excessive individualism and, at times, constrain choice. Societal expectations about who should be responsible for the family and for family health makes
reasonable the assumption that gender will play a role in the meanings constructed around genetic technology. Further, feminist ethics asks important questions about the structural and socio-environmental conditions that may contribute to cancer risk, rather than focus solely on risk factors that are supposedly within individual control.

Yet, with few exceptions, feminist arguments (just like those of mainstream ethics) remain within the purview of theoretical and abstract discussion. Empirical studies, assessing the influence of genetic information on people's everyday lives, are significantly missing from these discussions. In other words, ethicists and social scientists have raised key questions about informed consent, privacy and confidentiality, coercion and the possibility of insurance, employment, individual and group discrimination based on genetic information (Sherwin 1996; Knoppers and Godard 1998; Burgess, Knoppers et al. 1999; Sherwin and Simpson 1999; Sommerville and English 1999; Henderson 2001). Yet, few studies have attempted to assess whether these theoretical concerns actually affect people's lives. Also gone unexplored is the influence of genetic information on a person's moral identity or expression of moral agency. Namely, does genetic information change the way a person thinks about her/himself or her self in relation to others? Thus, I undertook this study with the goal of addressing some of these gaps in knowledge. Through the research that follows, I will endeavor to provide a detailed portrait of genetic testing from the perspective of those who come from hereditary cancer families.
CHAPTER FOUR:

Constructing Meanings

We had all felt the pattern of the Gulf, and we and the Gulf had established another pattern which was a new thing composed of it and us...We said, “let’s go wide open. Let’s see what we find, record what we find, and not fool ourselves with conventional scientific structures. We could not observe a completely objective Sea of Cortez anyway, for in that lonely and uninhabited Gulf our boat and ourselves would change it the moment we entered. By going there, we would bring a new factor to the Gulf. Let us consider that factor and not be betrayed by this myth of permanent objective reality. If it exists at all, it is only available in pickled tatters or in distorted flashes. “Let us go,” we said, “into the Sea of Cortez, realizing that we become forever a part of it; that our rubber boots slogging through a flat of eelgrass, that the rocks we turn over in the tide pool, make us truly and permanently a factor in the ecology of the region. We shall take something away from it, but we shall leave something too.”

--John Steinbeck and Ed Rickets, *The Log from the Sea of Cortez* (1941)

Introduction

This chapter presents the rationale for using an ethnographic approach in my dissertation research. As previously discussed, the purpose of this study is to provide rich contextual detail regarding the meanings, motives, concerns and values people bring to genetic testing. My aim is to understand whether genetic information influences how individuals think about themselves, relate to family and/or perceive responsibilities to others. Namely, does genetic information have the ability to influence a person’s sense of self or moral agency? I considered ethnography as the most appropriate methodology for the work because of its attentiveness to individuals’ perspectives and experiences. As well, I sought a methodology, which would allow me to examine participants’ experiences within the broader social and political context in which genetic technology is utilized.

In this chapter, I explicate the methods and procedures I used to conduct the research. I begin by reviewing the ethnographic tradition from which I have drawn. I address some of
the challenges to the methodology that have arisen over the past two decades. I also briefly and selectively discuss the contribution that feminist epistemology makes to critical social science inquiry. I describe how my approach endeavors to build on the tenets of ethnography while responding to recent criticisms. I then move to describe the practical aspects of my study. I begin by explaining how I got involved in this work. I provide an overview of the research process (participant recruitment, interviewing, and approach to analysis). I reflect on some of my original assumptions and how they were changed through the research process. The chapter concludes with a brief summary of the central themes of my dissertation research and the value of using ethnographic methods to explore those themes.

**Ethnography: an overview**

Based in cultural anthropology, ethnography has been used by researchers in other disciplines such as some forms of sociology, education, history, clinical psychology and even dentistry. For this discussion, then, I need to be clear about what the term means.

Hammersley and Atkinson (1995) describe ethnography as a set of research methods that is aimed at the study of social contexts, and James (1988) as the “translation of experiences into textual form” (p. 25). Denzin (1997) defines ethnography as a form of inquiry that produces written descriptions about the author and those written about. In this research, I adhere to the definition given by Deborah Britzman (1991). She writes: “An ethnography is a study of lived experience and hence examines how we come to construct and organize what has already been experienced” (p. 9). Lived experience alludes to the process in which individuals describe and give meaning to what happens to them. It is found in the stories that people tell about themselves and about the things that matter to them. It brings to bear the ways in which people live and make sense of their experiences in everyday life (Hammersley
and Atkinson 1995). Yet, lived experience does not occur in a vacuum; it reflects, reproduces and recreates our social world. Thus, as Britzman states, the purpose of ethnography is not only to describe lived experience, but to examine how in the course of depicting their own lives, individuals also construct culture.44 Because we live in a world characterized by hierarchy, ethnography also needs to give special attention to how experience is shaped by unequal power relationships. It needs to examine how people “define what is possible and desirable for themselves and others” (Simon and Dippo, 1986: 196).

In the past two decades, traditional approaches to ethnography have been the focus of intense debate. This debate has led to, what Denzin (1997) calls, a triple crisis: the crisis of representation, the crisis of legitimization and the crisis of praxis. The first crisis stems from challenging the assumption that ethnographers can capture and reveal lived experience. Traditional ethnography has proposed that through various methods (participant observation, interviews, fieldnotes), the researcher can come to know the subjects she is studying and represent their ‘reality’ in written text. Ethnographers have historically assumed, as Denzin (1997) writes, “that talk directly reflects subjective and lived experience. The literal translation of talk thus equals lived experience and its representation” (p.5). Critical45 theorists reject the notion that there can be a direct link between experience and text (Clifford

44 Building a bridge between culture and morality requires that I articulate what culture means to me. For this, I am guided by the work of James Clifford (1988). He argues against essentialist notions of culture as an ensemble of characteristic customs, behaviors, and beliefs. Rather, he contends that culture is something that happens between people; it is the “open-ended” and creative negotiation of language and meaning, the “dialogical interplay” of multiple voices. I also take direction here from Britzman (1991), who describes culture as a site “where identities, desires, and investments are mobilized, constructed and reworked” (p. 57). Similar to Clifford, Britzman rejects the notion of culture as static but views it as something that is fluid and changes over time.

45 Guba and Lincoln (1994) use the term critical theory to denote a number of theoretical positions including postmodernism, feminism, and post-structuralism. While representing different schools of thought, critical theorists share some fundamental tenets including the belief that inquiry (and thus knowledge) is socially constructed, and historically and culturally located. Critical theory has contributed to the understanding that “there is no clear window into the inner life of an individual. Any gaze is always filtered through the lenses of language, gender, social class race and ethnicity” (Denzin and Lincoln, 1994).
Language and writing are seen as productive, rather than mimetic; that is, they create and transform that which is being described (Denzin 1997). Furthermore, inquiry is not considered as neutral, but rather socially constructed, historically located and value-mediated.

The crisis of representation has also been fueled by the rejection of claims to absolute truth or objectivity in research (Gavey 1989; Clough 1992). “Feminist explorations of our realities, as women, have tended to produce different truths, thus casting suspicion on the idea of one reality and one truth” (Gavey 1989: 462). Further, feminists, people of colour and other marginalized groups point to power relations that have dominated ethnographic projects and shaped modes of representing knowledge (Clough 1992). They make problematic the question of how voices are heard, with what authority and whose knowledge is legitimated. Indeed, those involved in subaltern studies argue that ethnographic representations of colonial subjects say more about exploitive practices of the colonizers than the colonized (Spivak 1988). Those who have the power and material advantage get to authoritatively define what counts as truth or knowledge (Lather 1986; Gavey 1989; Lather 1991; Walker 1998). From a critical standpoint, then, ethnography is understood to be a social and textual construction. This does not signify the end to representation, but rather as Lather (1993) observes, the “end of pure presence.” (p. 675).

Besides the significant challenges to representation, ethnography has also faced a crisis of legitimization. Traditional standards for establishing validity -- that is, what counts as criteria for judging the legitimacy or authority of the research -- have been called into question (Lenzo 1995; Lincoln 1995; Denzin 1997; Whittaker 1999). While some scholars

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46 Marcus (1998) defines subaltern peoples as those subject to systemic domination, resulting from capitalist and colonialist political and economic practices.
argue for refining or broadening established criteria (Hammersley 1992), others call for a reconceptualization of validity based on relational, emancipatory (Guba and Lincoln 1989; Lincoln 1995) or 'transgressive'\textsuperscript{47} (Lather 1993: 685) approaches to research. Inherent to these approaches is a rejection of the rigid dualisms that have traditionally characterized research (objectivity and subjectivity, researcher and researched; knower and known) and a request for an interpretive, open-ended approach to inquiry. Within this debate, I found Smith (1993) particularly helpful. As he puts it:

> The task for interpretivists is to elaborate what lies beyond epistemology and beyond the idea there are special, abstract criteria for judging the quality of research...Interpretivists see criteria not as abstract standards, but as an open-ended evolving list of traits that characteristic what we think research should do and be like (cited in Lincoln, 1995: 275).

Lastly, Denzin (1997) uses the expression “crisis of praxis” to signify a shift in the vision of who research is for. Praxis refers to the seeking of knowledge not just for knowledge of, but knowledge for social change. Bound up with questions of representation and validity, praxis envisions research characterized by negotiation and reciprocity. It is committed, writes Lather (1991), to “critiquing the status quo and building a more just society” (p. 51). Relationship serves as its foundation.

Thus, as one moves from traditional ethnography to more critical positions, increased importance is attached to the following questions: What is the purpose of research? Whose goal is it intended to serve? Who is the subject of research? The ‘crisis of praxis’ has forced

\textsuperscript{47} Various alternatives to positivist conceptions of validity have been proposed. Constructivists (Guba & Lincoln, 1989; Lincoln, 1995) argue for an approach to validity that reflects a moral commitment to inquiry. Their criteria emphasize fairness, the learning of participants as much as the researcher, the open and democratic sharing of knowledge as well as the fostering and enabling of social action (Lincoln, 1995). Critical theorists call for an emancipatory approach to research, where validity is determined by the critical understandings it produces (Britzman, 1991; Simon and Dippo, 1986; Lenzo, 1995; Roman, 1993). Post-structuralists emphasize notions of validity that disrupt dominant and oppressive knowleges (Lather, 1993; 1991; 1986; Lenzo, 1995). To this end, transgressive validity reformulates validity as something that is “multiple, partial, endlessly deferred” (Lather, 1993: 675).
researchers to engage in research with greater political awareness. As well, it urges scholars to re-think and possibly shift the emphasis of their research. It impresses upon social science (and social scientists) the need to think of research as not only in terms of scholarship, but also in contributing to social justice and social change. It reflects a new commitment to study participants. For those committed to praxis, it is no longer acceptable to consider study participants as the object of research; they are now recognized as collaborators in the research process. It is this more 'egalitarian' approach to research – one that recognizes the challenges of interpretation, representation and the question of who the research is for (Whittaker 1999) -- that I aimed for this in this study.

Feminist contributions

At this point, I would like to say something about the contributions feminist theory has made to the research enterprise. At the core of many of the debates about ethnographic research are questions of epistemology. Epistemology refers to the source, derivation and justification of knowledge, or as Harding (1986) writes, “what can be known, by whom and by what means” (p. 3). Put another way, it is concerned with the nature of knowledge, the scope of knowledge and the reliability of knowledge claims (Hamlyn 1967).

One of the major contributions feminist thinking has made to epistemology and the rethinking of science in general has been its powerful critique of positivism (Wolf 1996a). Simply stated, positivism denotes the view that reality exists “out there” and that the researcher, following prescribed methods, can produce an objective account of that reality. It is based on the assumption that natural phenomena exist in fixed relations with each other, and that these relations can be discovered and known in consistent ways (Keller 1985). Thus, positivism is rooted in the belief that accurate scientific observation must be conducted by
neutral researchers “free” from the influence of personal interests (Baylis, Downie et al. 1998). Further, positivism supports a dualist/objective epistemology, meaning that the researcher and the researched are considered to be independent identities. The researcher, as well as the subject are “culturally and historically disembodied” because knowledge “is by definition universal” and objective (Harper 1996: 63).

Feminist epistemologists have been critical of positivist interpretations of objectivity (Harding 1991). They have also worked to re-conceive traditional research epistemologies and methods in order to address and understand women’s gender-specific experiences, insights and knowledge. Although there is no single theory regarding what constitutes women’s experiences and knowledge -- indeed, many claims that a single feminist theory would be neither possible or desirable (Code 1991; Roman 1993; Asch and Geller 1996) -- feminist standpoint theory offers a basis for challenging the kinds of scientific ‘truths’ that have been so alienating and oppressive to women (Harding 1986; Harding 1991; Harding 1993).

There are various versions of feminist standpoint theory, but they all share a common premise: that is, the structure of human activity has a direct influence on what may be known and how it is known (Harstock 1987; Smith 1987; Harding 1993). Feminist scholars maintain that difference in the social experience of men and women gives them different ways of looking at life and interpreting events, and hence, different standpoints. Aware of women’s exclusion in many realms, they call for research that starts from and builds on women’s experiences and activities (Olesen 1994). Women are seen to be in an epistemically privileged position to address central issues that affect them. Smith (1987), in particular, has created a feminist standpoint approach that allows women to theorize their experience out of
their own labour. She argues that women’s experiences provide a crucial vantage point for asking critical questions not only about women’s lives, but men’s lives and the relationships between them. She also argues that the only way one can know a socially constructed world is to know it from within. The “embodied subjectivity” of women researchers, that is their own knowledge and experiences, are thus crucial for creating knowledge and understanding the knowledge of other women (Smith, 1987).

In spite of concern for women’s lived experience, other feminist scholars have faulted standpoint epistemology on a number counts. Claims to theorize women’s lives have floundered on the same epistemological challenges levied at non-feminist views: “Not all women recognize the voice or experience theorized as theirs” (Walker, 1998: 57). The focus on gender as the primary locus of oppression suggests that there is an essential gender identity common to all women. Yet women experience gender in different ways depending on other dimensions of their identity (Roberts 1996). Standpoint theory has also been criticized for ignoring the intersections of class, race, ethnicity, sexual orientation and age with oppression (Lugones and Spelman 1983; hooks 1984; Collins 1990; Roberts 1996). As Alcoff and Potter (1993) put it, “Gender hierarchies are not the only ones in influencing the production of knowledge” (p. 3). Others see danger in assuming that one group’s perspective is less distorted, rather than just different from another (Tuana 1993); and others challenge the notion of a stable, personal gender identity and replace it with the notion of multiple, heterogeneous and contradictory selves (Hasnot, 1993; Trinh, 1991 - cited in Denzin, 1997).

Haraway (1988) offers an alternative to standpoint theory, which I found useful in thinking about my research. Arguing that the impartial standpoint of traditional epistemology is neither feasible nor desirable, she proposes an “a doctrine of embodied objectivity”
This approach evokes a view of knowledge as situated and positional. "Situated knowledges" are "marked knowledges" that portray the actual social locations (historical, national, generational) and positions (race, gender, class) of the researcher (Haraway 1991:111). Haraway stresses the importance of recognizing knowledge as shaped by people’s subjectivities: by the needs, desires, and ways of perceiving of those who construct it. But she does not privilege one person’s or group’s position over another. The task is not to determine which standpoint is best, but rather to understand how complex subjectivities are expressed in the production of knowledge. Related to this is her assertion that knowledge is partial: no one group or individual possesses it completely. In sum, Haraway urges theorists to reconstruct epistemology and conduct research on more self-conscious grounds.

Harding, responding to criticisms of standpoint theory, also recognizes the need for epistemology to look critically at relations, practice and assumptions. She calls this demand on knowledge "strong objectivity" (Harding 1993). Strong objectivity requires that the researcher put herself on the same "critical, causal plane" as the researched (p. 69). It requires reflexivity at every stage of the research process from the selection of problems to design of research to the collection and interpretation of data. It calls for institutions and research communities to invite and reward evaluation and criticism of knowledge claims based on democracy-advancing projects. It requires that research does not feign neutrality, nor does it suppress relevant criticism from diverse viewpoints. Strong objectivity, as Walker (1998) adds, "requires critical techniques to reveal the specific powers and limits of the discourses and instruments that enable us to know. It needs research on biases and saliences
and the specific ways they make possible what we know and what we can’t and what we
don’t” (p. 59).

For feminist epistemologists, then, questions about authority and representation
remain paramount. Feminist inquiry insists on asking: what knowledge is produced, under
what conditions, about whom and for whom (Wolf, 1996a). It directs us to look at the
intersection between gender, class, age, ethnicity and other social constructs on knowledge
claims. Each of these issues seeks to make overt the linkage between power and knowledge.
They are also linked to questions regarding research aims and methodology. Although
feminist epistemology is not equated with a predetermined methodology or method, it
impacts both (Harding 1993; Oakley 2000).

Feminist research is done to understand the everyday experiences and knowledge of
women and hopefully empower them through the research process (Smith 1987; Anderson
and Jack 1991). It is based on the premise that every woman (or man) has something
important to say. Research grounded in a feminist epistemology means challenging the
existence of value neutrality at every stage of the research process (Whittaker 1994; Baylis,
Downie et al. 1998). It means finding ways that represent adequately the authority of the
participants and account for the standpoints/positions of the researcher in both analytic and
methodologic terms. Although these criteria are not necessarily unique to the feminist
project, they are central to them. They have also served to spur much thinking on egalitarian
approaches to social science research and the politics of ethnographic writing (Abu-Lughod
1990; Anderson and Jack 1991; Lather 1991; Reinharz 1992; Behar and Gordon 1995; Wolf

Indeed a number of feminist scholars (Harding, 1993; Reinharz, 1992; Wolf, 1996a) and other theorists
(Denzin, 1997 Lincoln, 1995) insist that methodology, epistemology and ethics are all inextricably linked. In
other words, knowledge is seen as a matter of practice as well as morality in that it has implications for the way
we live.
Building the ethnographic terrain

As introduced in Chapter 1, this study sought to gain insight into how genetic testing is experienced from the perspectives of individuals and families at risk for breast/ovarian cancer. In attending to the details, complexity and situated meanings, I wished to explore what it means for women to be identified, and to identify, themselves or other family members at risk for hereditary breast/ovarian cancer. I wished to understand what is the significance of predictive testing to people’s everyday lives. Does it influence how individuals think about themselves, relate to others or perceive responsibilities to family members as well as to the community at large? Does genetic knowledge impact those things that people care most deeply about and take responsibility for? In addition to constructing knowledge congruent with participant’s understandings and experiences, one of my explicit intentions was to create knowledge that may improve care for those undergoing testing and their families in the future.

In approaching my research, I drew on the traditional tenets of ethnography, while attempting to respond to insights developed through recent debates about representation, praxis and feminist inquiry (Haraway 1988; Lather 1991; Stacey 1991; Harding 1993). I followed the lead of Sherwin (1992, 1998), Tong (1997), Walker (1998) and others, who stressed both the importance of contextual details in giving moral conceptions their meaning and the broader social and political context of these terms. I shared Walker’s (1998) view that moral understandings are embedded in particular settings with ongoing forms of social
practice structured by institutional patterns. These are not based on any mind independent reality, but reflect the consciousness, values and intentions of a historically-located culture.

Thus, my dissertation research employed ethnography (informed by critical and feminist theoretical perspectives) to gain insight into how genetic testing is experienced from the perspectives of individuals and families at risk for breast/ovarian cancer. I proceeded from a constructivist position; that is knowledge and reality are historically and socially created, influenced by cultural, political, economic, and gender values. I also took as a starting point that anything I wrote would be mediated through my own life experiences and biases. I was intrigued by postmodern and post-structural thought, which challenges the notion of single identities and universal categories (such as women). I agreed with Clifford (1988) that ethnographic writing is “complicated by the action of multiple subjectivities” (p. 25). Yet, at the same time this did not imply to me that we cannot describe social phenomena in a thoughtful manner.

Research Design

Having described the methodological approach from which I proceeded, I now move to the more practical aspects of this study. This section focuses on some of the details of conducting my doctoral research including recruitment strategies, participation rate, interview design and thematic analysis. It also documents my efforts to remain reflexive about the research and analytic process. In accordance with ethnographic methods, in-depth interviews, participant observation and fieldnotes were my primary sources of data collection (Hammersley and Atkinson 1995).

While I adhere to a constructivist philosophy, I am also a realist and do not view these positions as mutually exclusive. As Schwandt (1994) so aptly observes: “One can reasonably hold that concepts and ideas are invented (rather than discovered) yet maintain these inventions correspond to something in the real world” (p. 126)
As described in chapter 1, my research was part of a larger study, the aim of which was to compare the ethical and moral dimensions of genetic risk for Huntington Disease and breast/ovarian cancer. Drs. Michael Burgess and Douglas Horsman were the principal investigators of this study. I was employed as the data manager/coordinator for the breast/ovarian side of the research from March 1998 to March 2001. Working in conjunction with Dr. Burgess and Dr. Sue Cox (data manager/coordinator for the Huntington Disease side of the study), I contributed to the design and development of research strategies aimed to examine the social and moral experiences of genetic testing for breast/ovarian cancer. The objectives of this study, which received funding from the Canadian Breast Cancer Foundation, the Huntington Society of Canada and the Earl and Jennie Lohn Foundation, are detailed in Appendix 2. The project received final ethics approval from the BC Cancer Agency in January 1998.

The topic of my dissertation branches out from the focus of objective one of the comparative study – “to describe the moral experiences associated with genetic testing for Huntington Disease and BRCA 1/2 from the perspectives of participants and their family members.” My particular focus -- the effect of genetic information on understandings of moral identity, agency, responsibility and self -- evolved from the research itself.

**Sampling and recruitment**

Participant selection involved a process called “purposive sampling,” described by Merriam (1988) as a sampling technique where the researcher selects on the basis of known characteristics or experiences. This sampling is driven by the need to obtain information about particular kinds of populations, situations, or experiences. In this research, sampling

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50 See Appendix 3 for copies of the letter of introduction and informed consent. The latter included the participant’s right to withdraw from the study at any time. It also detailed strategies for anonymizing the data and ensuring confidentiality.
involved seeking participants who were eligible for, or had undergone genetic
counselling/testing at the B.C. Cancer Agency’s Hereditary Cancer Program (HCP). Criteria
included participants of different ages and who had experienced familial cancer in different
places (geographical locales) and circumstances. Both women and men were invited to
participate in the study. However, women comprised the vast majority of those receiving
counselling and testing and likewise, comprised the majority of study participants.

Recruitment occurred by several means. Throughout the study, I received
considerable assistance from two genetic counselors at the BC Cancer Agency’s Hereditary
Cancer Program to find study participants. Based on the above criteria, they contacted
individuals who had already undergone genetic counselling/testing, told them about my
research and asked their permission to give me their names and phone numbers. If given, I
then followed up this initial contact with a telephone call. I described the goals and objectives
of the study, what would be involved and invited them to participate. After the initial
discussion, I also sent potential participants an information letter and informed consent form
that outlined the study purposes to help facilitate their decision (see Appendix 3). I
encouraged potential participants to take some time to consider their participation in the
study. I also informed them they could withdraw at any time. Written consent for the
individual interview was obtained when I conducted the interview itself.

Recruitment of family members occurred almost simultaneously. By this I mean, if
the participants I contacted expressed willingness to participate, I requested their support in
asking other family members (siblings, parents, spouses, adult daughters) whether they might

51 These individuals were “index cases” for their families, meaning they were the first in their families to seek
genetic counselling from the HCP.
be interested in participating in the research.\textsuperscript{52} In fact, the greatest number of participants came through this means as it was rare that just one member of the family had been tested. For example, if a woman in a kinship had been tested, frequently a number of siblings or other relatives had undergone testing as well. I kept in mind that they might feel pressured to assist me, and emphasized they should feel under no obligation to do so. As with the genetic counsellors, they made initial contact with family members, and asked their permission to give me their phone numbers. If obtained, I followed up by phone to ascertain the willingness of the family members to participate. Further access to study participants resulted from my attendance at genetic counselling sessions. Here, I met people receiving counselling and asked them directly whether they would like to participate in the study. This allowed me to recruit some people who received genetic counselling but decided not to be tested.

There were two exceptions to these three main methods of recruitment. I met one participant through a social worker at the BCCA, who like the genetic counsellors, obtained the individual's permission first so that I could contact her. This participant, in turn, introduced me to a friend of hers who had also undergone BRCA1/2 testing. She had told the latter about the study and her friend asked whether she could participate as well.

Similar to Cox's (1999) observation in Huntington Disease, people contacted demonstrated an incredible willingness to participate in the research. Of 59 people contacted, only six declined to participate. My final research sample (Table 1) consisted of 53

\textsuperscript{52} Beeson and Doksum (2001) call this form of sampling, 'cascade sampling.' It begins with the 'index' person or carrier and having them refer the researcher to other biological relatives or significant others.
Table 1

Recruitment and Participation Rate

<table>
<thead>
<tr>
<th>Participation</th>
<th>Female</th>
<th>Male</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Invited to participate in study</td>
<td>50</td>
<td>9</td>
<td>59</td>
</tr>
<tr>
<td>Accepted the invitation</td>
<td>45</td>
<td>8</td>
<td>53</td>
</tr>
<tr>
<td>Declined the invitation(^a)</td>
<td>5</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Participation Rate</td>
<td></td>
<td></td>
<td>89.8 %</td>
</tr>
</tbody>
</table>

\(^a\) One candidate told me directly that she did not wish to participate in the study. Two declined through a family member, and one did not return her informed consent form to me. I took this to mean that she did not want to participate. One other person initially agreed to participate in the study, but later when I left a message on his answering machine to set up an interview time he did not call back. I tried to reach him three times and then took his lack of response as meaning he did not want to participate anymore. The last person met with me. However, from the outset she seemed very uncomfortable with the interview and after five minutes of talking, I asked whether she wanted to continue or not. She declined at this point.
participants (45 women and eight men). Forty-nine participants were from ten (biological) families; four individuals were interviewed without additional family members. Table 2 represents a further breakdown of the research sample: thirty-nine participants underwent testing, six declined testing even though they met eligibility criteria; three participants from the same family (one with breast cancer, two without) had sought testing but were waiting for the index test results before proceeding. In addition, I had the opportunity to interview four spouses and one son of an individual who underwent testing. Table 3 provides information on the participants’ test results and Table 4 details baseline demographics. Educational background varied: 38% had completed high school; 49% had obtained further vocational training or university.

I based the number of participants recruited to the study, in part, on achieving thematic completeness. In other words, I conducted interviews until I heard the consistent replication of certain themes and findings. Because the goal of the investigation was discovery and understanding, not generalization, the sample size did not need to be large or random (Waxler-Morrison, Doll et al. 1995). Yet at the same time, I realized that I needed to have a ‘minimum’ sample size in order for the research to be considered credible by a clinical audience. Thus, while I felt achieved saturation of categories at about 40 interviews, I

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53 It is important to point out, however, that this high participation rate does not reflect the actual demand for genetic testing. According to Karen Panabaker, genetic counsellor at the HCP, approximately one-third of those who have genetic counselling actually elect to have the test. (This low participation rate has also been observed to occur in other diseases for which predictive testing is available). Thus, the participants in this study were a select, highly motivated group and should not be considered representative of all people who are eligible for genetic testing based on family history.

54 The comparative study, based on previous research with Huntington Disease, aimed to address the moral experiences of both the person tested and family members. The reasoning behind this is that genetic disease affects families and not just individuals. Yet, in the breast/ovarian cancer group, most of the family members of those tested are sisters, mothers, female cousins, etc., who tended to opt for genetic testing themselves. Thus, the original distinction between those who were tested and those who were family members did not hold here; participants were usually both. The only participants who fell out of this group were spouses or partners of those who were tested, and thus not eligible for testing. I also included one son in this group. He was from the family awaiting test results and at this point, was vague about what he thought about testing for himself.
made the decision to continue data collection until I had at least 50 interviews. This endpoint is somewhat arbitrary, but I thought a larger number would help me establish credibility with audiences who are more familiar with quantitative methods. Yet, I also wish to point out that my very last interview raised issues concerning genetic testing that I had not considered previously. Thus, although we cannot conduct research indefinitely, I tend to think that the term 'data saturation' is misleading. Even with quantitative data, it is probably an unattainable goal.

As previously mentioned, I sought to gain an understanding of women's experiences of genetic testing for hereditary breast/ovarian cancer. While I do not disregard substantive variables that distinguish women, such as class, race, or religion, I did not address these specific factors in detail. The small sample size of this study did not permit meaningful comparisons. Further, the study population was very homogeneous: participants were all of Caucasian descent. This sample is representative of the population who currently seeks genetic testing services at the BCCA as a whole, but nonetheless it is important to recognize that differences in ethnicity might engender different kinds of attitudes towards and experiences around testing. Also, with the exception of the first family I interviewed (five members in total), I chose to restrict recruitment to people from families in which had mutation had been detected. I narrowed the selection criteria in order to better address my research question: does genetic testing influence how individuals think about themselves and relate to others? My interview with the first family made me realize that if the testing process had not begun, participants could only speak to their anticipation of what genetic knowledge
Table 2

Genetic testing for BRCA1/2 mutations

<table>
<thead>
<tr>
<th>Participant Categories</th>
<th>Female</th>
<th>Male</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Received genetic testing</td>
<td>34</td>
<td>5</td>
<td>39</td>
</tr>
<tr>
<td>Declined testing</td>
<td>6</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Awaiting test results before proceeding further</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Family members, not eligible for testing</td>
<td>2</td>
<td>3</td>
<td>5</td>
</tr>
</tbody>
</table>

Table 3

Genetic test results for BRCA1/2 mutations

<table>
<thead>
<tr>
<th>Participant category</th>
<th>Female</th>
<th>Male</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive results</td>
<td>25</td>
<td>3</td>
<td>28</td>
</tr>
<tr>
<td>Negative Results</td>
<td>9</td>
<td>2</td>
<td>11</td>
</tr>
</tbody>
</table>
### Table 4

**Demographic Profile of Participants**

<table>
<thead>
<tr>
<th>Demographic Category</th>
<th>Demographic Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>45</td>
</tr>
<tr>
<td>Male</td>
<td>8</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>20-30</td>
<td>6</td>
</tr>
<tr>
<td>31-40</td>
<td>13</td>
</tr>
<tr>
<td>41-50</td>
<td>17</td>
</tr>
<tr>
<td>51-60</td>
<td>11</td>
</tr>
<tr>
<td>61-70</td>
<td>6</td>
</tr>
<tr>
<td>Older than 70</td>
<td></td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>10</td>
</tr>
<tr>
<td>Married</td>
<td>32</td>
</tr>
<tr>
<td>Common-law</td>
<td>2</td>
</tr>
<tr>
<td>Separated/divorced</td>
<td>8</td>
</tr>
<tr>
<td>Widow</td>
<td>1</td>
</tr>
<tr>
<td><strong>No. of Offspring</strong></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>17</td>
</tr>
<tr>
<td>One</td>
<td>7</td>
</tr>
<tr>
<td>Two</td>
<td>11</td>
</tr>
<tr>
<td>Three</td>
<td>7</td>
</tr>
<tr>
<td>Four</td>
<td>7</td>
</tr>
<tr>
<td>Five</td>
<td>2</td>
</tr>
<tr>
<td>More than five</td>
<td>2</td>
</tr>
<tr>
<td><strong>Level of Education</strong></td>
<td></td>
</tr>
<tr>
<td>&lt; High school</td>
<td>3</td>
</tr>
<tr>
<td>High school diploma</td>
<td>20</td>
</tr>
<tr>
<td>Diploma/Technical School</td>
<td>16</td>
</tr>
<tr>
<td>University</td>
<td>10</td>
</tr>
<tr>
<td>Unknown</td>
<td>4</td>
</tr>
<tr>
<td><strong>Employment Status</strong></td>
<td></td>
</tr>
<tr>
<td>Working full-time</td>
<td>30</td>
</tr>
<tr>
<td>Working part-time</td>
<td>6</td>
</tr>
<tr>
<td>Self-employed in the home</td>
<td>3</td>
</tr>
<tr>
<td>Unemployed</td>
<td>4</td>
</tr>
<tr>
<td>Retired</td>
<td>7</td>
</tr>
<tr>
<td>On leave</td>
<td>3</td>
</tr>
<tr>
<td><strong>Residence</strong></td>
<td></td>
</tr>
<tr>
<td>Greater Vancouver</td>
<td>20</td>
</tr>
<tr>
<td>Vancouver Island</td>
<td>11</td>
</tr>
<tr>
<td>Interior, eastern B.C.</td>
<td>17</td>
</tr>
<tr>
<td>Other (other provinces, the United States)</td>
<td>5</td>
</tr>
</tbody>
</table>
might mean to them. It is quite possible their beliefs, reactions or suppositions might change after they had received their test results.

Participant Observation

Although interviews with participants comprised the primary source of data, observations also augmented the study. Merriam (1988) describes observation in qualitative research as ranging from complete participation to complete observation. My study tended toward the latter, with genetic counselling sessions serving as the primary site for these observations. I spent approximately 50 hours observing genetic counselling sessions with two different genetic counsellors at the Hereditary Cancer Program, BCCA. This kind of participation was informal and general. Yet, it greatly enhanced my understanding of how genetic information is presented, discussed and shared within the clinical setting. It gave me insight into people's motivations for seeking genetic testing, as well as types of concerns that arose with familial cancer. I recorded my observations with field notes (Emerson, Fretz et al. 1995), which I took during or immediately after the session. I used these later to identify topics that would shape the interview.

As part of my fieldwork, I also attended monthly clinical review meetings of the HCP. (I began attending this monthly meeting in September of 1997 and continue to date). These meetings provide a forum where genetic test results from individual patients were discussed. Attending the meeting were specialists from diverse disciplines including medical genetics, genetic counselling, cytogenetics, radiation and medical oncology, gynecology,

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55 To be clear, these were persons who were eligible to be tested but had just begun the testing process.
56 I call myself a "complete observer" during the sessions since I did not ask questions; my intent here was to be an non-intrusive as possible. However, I recognize that as Atkinson & Hammersley (1994) point out, just my presence in the room is a form of participation. I was part of that social world and undoubtedly my presence changed the dynamics of the counselling session. As well, I had the opportunity to talk with clients directly during the 5 to 10 minute period when the geneticist left the room to update the counsellor prior to the latter conducting her part of the counselling session. This might be considered a form of more direct 'participation.'
family practice, nursing, social work, ethics and medical anthropology. Here, the significance of test findings was discussed on a case-by-case basis and medical recommendations were made for patient treatment or follow-up. This group also served as a sounding board for genetic counsellors, who needed to discuss the implications of changing genetic knowledge on standards of care, clinical practice and ethics. The opportunity to observe these meetings proved invaluable in helping me to understand how genetic technology is interpreted and incorporated into clinical practice, as well as how professionals respond to the constantly evolving nature of genetic information. I also participated at times, describing aspects of my study that I thought relevant to the discussion. As with the genetic counselling sessions, observations were informal and recorded with field notes taken during the meetings.

**Interviews**

In-depth interviews comprised the core of this research. With few exceptions, the interviews were conducted in the participant’s homes or another place of their choosing. Participants lived in various locales throughout BC including the lower Mainland, Vancouver Island, the Interior and the Kootenay-Boundary region. In addition, I interviewed two participants by phone. The latter were siblings of test candidates whom I had met in B.C., but lived out of province. They had received genetic counselling and test results through programs other than the HCP (one in Alberta and the other in the U.S). I also conducted a second interview with six participants, approximately a year after I first interviewed them. The interviews ranged from half an hour to two hours in length. All were audio-taped (with consent) and transcribed.\(^{57}\) In an effort to ensure anonymity, all participants were given

\(^{57}\) To transcribe someone’s words to text, however, involves far more than transcription. As Denzin observes: “A written text become a montage—a meeting place where “original” voices, their inscriptions (as transcribed texts), and the writer’s interpretation come together” (1997, p. 41). When stories are inscribed into text, they must not be read as essential truths, but as constructions of particular events.
pseudonyms. Further, the names of towns, hospitals or specific locations that may identify the participants were deleted from the documentation.

Although they had a stated purpose, the interviews were open-ended. I had come to this work with a view of the interview as a conversation, and with a preference for the participant to raise topics and issues she/he finds most important. The interview covered range of topics, including family and personal history of breast/ovarian cancer, reasons for seeking test, and experiences with counselling/testing and the impact this information had on their lives. Appendix 4 lists the questions used as prompts if these topics did not come up naturally in the conversation. Whenever possible, I gave the participant a copy of these questions prior to the interview (along with the information sheet about the study), so that she/he could have an idea of what direction the conversation might take. The sequence and use of specific questions were not fixed, however. The way I used them (if at all) varied from one interview to the next.

The interviews were conducted in two main phases: July-September '98 (29 interviews) and July-September '99 (20 first interviews plus 6 second interviews). I also conducted four additional interviews, two in May 2000 and two in June 2001. While stepping out of the field was necessary for me to fulfill other academic and family obligations, I found the experience to be immensely valuable. The ability to enter, step out and then re-enter the field was integral to my growing understanding. It gave me the opportunity reflect and develop some initial constructions and then explore, elaborate or re-

58 The interviews I conducted in 2000 were based on contacts I had made the previous summer. Scheduling difficulties made it more convenient to hold the interviews the following year. The two interviews I had in 2001, however, were a result of ‘theoretical sampling’ in which I tried to find individuals whose perspectives were contrary to my emerging categories. For example, when a social worker told me about someone who experienced family disruption because of genetic testing, I asked her if she could ask this particular individual if she would be interested in participating in my study. The client expressed great willingness, and also told a friend who had undergone genetic testing too about the study. This friend then requested that I interview her as well.
negotiate these constructions with new participants who I later met. I found myself asking myself: Did my initial constructions have any resonance with what others were now telling me? What had I missed? How similar, different or contradictory is what I am hearing now from other stories I had been told? The process allowed me to clarify emerging themes with participants, and thus provided an important means of validating the research.

Analysis

I approached this work recognizing that research is not a linear process that can be divided into discrete sections (Merriam 1988; Hammersley and Atkinson 1995; Sandelowski 1995). Rather, it is an integrated, multi-faceted process that is affected by both what precedes and follows it. Interactions with participants and colleagues, my reading of the literature, as well as on-going reflections about the stories I heard shaped how I conducted the interviews. These various elements worked in concert as I collected the data and likewise, as I proceeded with the analysis. Indeed, I believe that my analysis began to take shape with the first question I asked.

Hammersley and Atkinson (1995) maintain ethnographic analysis is an iterative process that involves developing categories and conceptual themes and discussing, verifying and extending these with participants. I began the formal analysis by first reading the interviews through several times. Most comfortable with pen and paper, I wrote notes and brief summaries and attached these to the hard copies of the transcripts. From these notes and summaries, I identified categories. For example, cancer experience, reasons for genetic testing, impact of genetic information, advantages, disadvantages and disclosure served as some of the initial categories. Comparison of categories within and between interviews (as well as field notes and reflective inquiry) enabled further clarification of meanings,
relationships, analytic concepts and themes (Huberman and Miles 1994; Hammersley and Atkinson 1995). At this point, I transferred the data into a computer program (QSR N5) for easier management.

Trustworthiness and validity

As previously stated, social theorists have claimed that a broader rendering of validity of research is needed. Yet, reaching agreement on what criteria to include in establishing the validity of research is not always easy (Oakley 2000). I took direction mainly from Lather (1991, 1986) who calls for an approach to validity premised on a re-conceptualization of construct validity, face validity, catalytic validity and triangulation. She argues that construct validity must entail a systematized reflexivity, which gives some indication of "how a prior theory has been changed by the logic of the data" (1986: 67). It requires a critical evaluation of how one's beliefs, concepts and views are modified by an encounter with the participants: Face validity is integral to establishing data credibility and involves member checks with participants. Catalytic validity is reformulated to include the participant in examination of self-understanding and thinking through the research process. Triangulation goes "beyond the psychometric definition of multiple measures to include multiple data sources, methods and theoretical schemes" (1986: 67).

In this study, construct validity entailed an ongoing evaluation of my assumptions and beliefs and how these were challenged, explored or made evident by discussions with the participants. The keeping of a research journal was integral to this process. I used this journal to describe situations, people and places being observed as well as to document my ongoing reflections about the research. However, this was not a neat, tidy process. Although I recorded observations and thoughts following each interview, often questions or insights
came to me at totally unexpected moments. On numerous occasions, I found myself grabbing for pen and paper to jot down ideas that came to me outside of the research situation. I would then later copy these thoughts (or staple the bits of paper) into my research journal. Other times, family responsibilities precluded my ability to sit and down and write out my reflections after returning from the field. In these cases, I recorded (audio) my observations and thoughts and later transcribed them. I elaborate further on reflexivity as a process in the following section.

I considered face validity as an integral part of the interview itself. My many years in journalism, as well as my Master’s work, had taught me that I should never take anything participants’ told me for granted. I had learned that it was a mistake to draw my own conclusions without verifying my interpretations with participants first. Thus, I routinely asked participants during the interview: “Do I understand you correctly to say... Am I right in saying that you think ... Is this what you mean by...?” I incorporated these questions into the interview in an effort to ensure that my interpretations most accurately represented the participant’s thoughts and intent. Guba and Lincoln (1989) suggested that taking data/interpretations back to participants ought to be part of establishing trustworthiness. However, given the large number of participants in this study, return of transcripts and thesis analysis to them was a practical impossibility. As previously mentioned, I sought

59 Also, based on my Master’s work, I wonder whether this practice does more to assuage the researcher’s desire to ‘reduce’ power imbalances between them and the researched, than it does to enhance equality. For my Master’s thesis, I interviewed nine teachers and returned the transcripts and pertinent areas of data analysis for their review. Most of these teachers said they felt comfortable with what was said in the interview and did not feel the need to review it. Further, they did not have the time. A few who read the transcripts/analysis were more embarrassed by how they spoke (e.g. poor grammar, incomplete sentences and shifting thoughts) than anything else. Although this practice is clearly necessary for some areas of research, I have come to believe that there is nothing inherently ‘emancipatory’ about returning data to participants, as there is nothing inherently ‘oppressive’ about not checking with them. I do not wish to imply that we do away with respondent validation, but I do think that this practice does not always have the guaranteed effect. In fact, some of our ‘emancipatory’
respondent validation by discussing my interpretations, emerging themes or checking for resonance with new participants I interviewed. I also sought feedback from a social worker and the geneticist at the HCP about certain constructions as the analysis evolved.

My ability to foster catalytic validity, as defined by Lather, was moderate. However, participants frequently told me that they enjoyed partaking in the interview process. Most participants said they valued having the opportunity to tell their story, especially if it could assist in research or help someone else. Others said the interview benefited them ‘therapeutically’; they told me it aided them in working through issues related to genetic testing. Thus the research process appeared to have helped some participants in self-expression or self-understanding. Catalytic validity was more evident, however, in discussions with clinicians at the HCP. Rather than waiting until the analysis was complete, I informed some clinicians early on about aspects of the data that I thought were immediately relevant to clinical practice. They told me they appreciated this information and said they would use these findings to inform counselling practices. Another time I gave a Medical Rounds presentation on my findings, after which some clinicians said it made them think differently about how genetic test information should be delivered. Thus, I came to think of catalytic validity as occurring at different levels throughout the research process: from the participant, to clinician and eventually to the system. I also hoped that knowledge derived practices may be perceived as burdens by those who participate in the research. As Acker, Barry and Essevold so aptly remark: “An emancipatory intent is no guarantee of an emancipatory outcome” (1983:431).

Consciousness-raising has been suggested as a means of achieving validity. However, an inherent danger in this approach is that it assumes that some people are more conscious, and thus more superior, than others. As Wolf (1996a) puts it: “Consciousness-raising implies that someone, usually the researched, is less than fully conscious and needs to have her consciousness raised by someone else, the researchers, who true and superior conscious has already been raised and who therefore know what the researched needs to know about her life” (p. 26). Recognizing that this kind of approach can be oppressive in itself, feminists have written about the need to become more cautious in imposing judgments and assuming they know what direction social change should take (Gluck and Patai, 1991). I apply the same reasoning to catalytic validity. I believe we have to be cautious in assuming that our research should necessarily spur participants to reflect, change or think differently.
from the study itself would serve as a catalyst for change, in that study findings could be used to identify the kinds of interventions needed to shift the allocation of health resources towards priorities identified by users of this technology, or to provide some suggestions on how best to support people with their concerns.

Triangulation of data included different sources: taped interviews, field observations, respondent/clinical validation and personal reflections. My goal was to detail the diversity, ambiguity and contradictions I observed, while at the same time, trying to characterize commonalities generated by experiences with this particular technology.

**Reflexivity**

Thus far, I have described the technical details of the study: where and when it occurred, recruitment strategies, the interview schedule and so forth. Yet, an ethnographic study is far more than number of participants involved or the length of a particular interview. Ethnography involves the study of people in interaction (Haig-Brown 1992). Epistemologically, it is based on the position that as people interact they create their social realities and derive meanings about events in their lives (Mead 1934; Blumer 1969). The researcher is not separate from, but part of this interaction. Indeed, my interactions with participants raised new issues for me at each stage of the research and analytic process. I will reflect on some of these here.

**Ethnographic tools revisited**

People doing ethnographic research engage in a process called gaining access. Yet, I agree with Haig-Brown (1992) when she writes: “For me, gaining access conjures up a vision of breaking down a gate or coming in with a research warrant. I prefer to think of the start of research in which I participate with other human beings as beginning a relationship”
(p. 97). Although arrogant to describe myself as friend, it was important to me that the people I interviewed saw me as a respectful and caring, someone whom they could trust. I looked at the interview, not as a place to have my questions answered, but as an opportunity for deep conversation. I hoped that the relationships I developed with participants – however brief – would provide a mutual opportunity to explore the meanings around genetic testing and living with familial cancer. Ultimately, I hoped that our collaboration would produce the kind of understandings and knowledge that participants would view as beneficial to themselves as well as to others.

Nonetheless, one of my major concerns as “researcher” was my total lack of experience with cancer. Although I had first-hand knowledge about other kinds of familial illness, both my immediate and distant family had escaped the trauma of this particular disease. I worried that because I did not share a cancer history, I might be perceived as an outsider to this community and lacking authenticity. Indeed, in asking me about motivations to pursue this work, participants frequently questioned whether I, or a close family member, had had breast/ovarian cancer? I could only tell them ‘no’; that I was learning about living with cancer through the stories they and others had told me. However, as I progressed with the research I realized that cancer (although significant) was just one part of a person’s identity. In fact, I was surprised at the degree to which parenthood frequently took precedence over other aspects of identity in framing experiences around cancer. I found myself increasingly conscious that my rapport with participants was strengthened by my status as a mother. As a mother of four-year old commented after asking me whether I had children:

It is funny because I have friend who is older, and I was trying to explain to her something about children. And I said I don’t mean to be obtuse, but I said you cannot
understand it. [She said] “What do you mean I can’t understand it?” I said people
would explain it to me before I had children, I didn’t understand.

I cite this example not to claim there is a difference between mothers and non-
mothers, nor to insinuate that parents have special insight into doing this kind of research.
Rather, my point here is to illustrate that as researchers we draw on different aspects of our
identities in creating relationships with participants (as do participants with us). My fear that
I would lack credibility in the eyes of participants diminished once I realized that we shared
other experiences and interests. Yet, while my familiarity with parenthood created an
opening for discussion with many participants (as did my identity as ‘researcher’ open the
doors with others), I also began to question the assumption that it was our particular
positions, role or identity claims that give the researcher credibility. Indeed, I have come to
disagree with the view that because of a shared history, identity and presumably shared
understandings, only certain groups have a legitimate vantage point from which to do
research with others. This is not to deny the unique understanding that arises from being part
of a particular group, or living with a particular condition. But groups, as Fee and Krieger
(1993) remark, are always socially constructed. Actual people overlap in many ways. There
is no question that ethnography, like other forms of research, requires ongoing scrutiny. We
must continually ask ourselves how our own experiences and values structure the research
and whether we are participating in another form of oppression through the type of work we
do. But, I think it is the researcher’s capacity (and participant’s sense of that capacity) to
listen, to understand sympathetically and intellectually, and to reciprocate in ways that are meaningful to the participant that form the basis for an authentic relationship here. \(^{61}\)

**Telling and listening**

When I first began the interviews, I was strongly influenced by a body of literature that viewed genetic testing as another form of medicalization and control. Abby Lippman (1998) coined the term geneticization to describe the tendency of medicine to distinguish people, behavior and illnesses on the basis of genetics. Geneticization, she wrote, "creates whole new groups of disorders, "sufferers,” and putative populations" (p. 67). Just as mammography screening is presented as a means of saving lives, she argued that genetic testing promotes the view that women can impact cancer mortality if they know their genetic status. In doing so, predictive genetics makes the individual responsible for her health. It positions her as the locus for change by treating a genetic predisposition as an individual problem (Sherwin 1996; Lippman 1998; Lock 1998; Finkler 2000). The implicit expectation, as Sherwin (1996) observed, is that an individual must learn that for which she may be susceptible and then do something to reduce her risk. At the same, surveillance strategies and surgical measures are of uncertain efficacy. These theoretical arguments were echoed by an observation made my thesis supervisor during a HCP case conference. He queried the logic of proposing a treatment for genetic risk (prophylactic mastectomy/oophorectomy) that was considerably more severe than the treatments given to women who actually had breast cancer itself.

Thus, I entered the study with the assumption that genetic testing represented another means of medical control over women’s bodies. I suspected that I would find participants

\(^{61}\) That said, I do think there are times when ‘group affiliation’ really opens the door to different kinds of conversation. For example, I think female participants told me things because of our ‘shared’ identity as women that they probably would not have disclosed to a male researcher. The reverse would be also true.
who had been pressured into genetic testing by biased, but well-intentioned physicians, who believed genetic testing was the responsible thing to do. I also thought that I would find women who demonstrated ‘resistance’ to the ideology of genetics and genetic testing. In addition, I held the assumption that knowledge of a genetic mutation would impact people negatively more often than not. I thought that knowing one had a genetic mutation would be largely perceived as a death sentence; that this information would become all encompassing in people’s lives.

Yet, it quickly became impossible for me to maintain these assumptions in the face of what I was told. The disjuncture between theory and actuality grew strikingly evident as I listened to participants’ accounts of familial cancer. For the majority, cancer was not a one-time event, or a risk probability, but something that was ever-present in their lives. Extending across generations, it had a timeless quality. It affected people’s understandings of their present and future selves, as well as their past. It affected their relationships with others and how they viewed themselves in the world. Although meanings of cancer can be evaluated through examination of other social-cultural and political ideologies, the disease had a palpable presence here. This did not mean that participants automatically accepted genetics as the sole cause of their cancer (or that they ignored social/environmental explanations), but they – like most people -- would use genetic technology or any medical test if it could alleviate future suffering.

This was a humbling experience. More than anything, it reminded me that my approach to interviewing must remain open if I was to gain deeper understanding of the impact of new technologies on people’s lives. These early interviews provided a different direction for the thesis. I realized I could not discuss the impact of genetic testing without
exploring what it meant to live with and know hereditary breast/ovarian cancer first. Participants' stories shared some features, but also differed from personal experience narratives of breast cancer that I had read in the popular literature (Rollin 1976; Lorde 1980; Kahane 1990; MacPhee 1994). Indeed, I began to question the relationship between various critiques and ideologies around genetic testing and participants' life experiences with breast/ovarian cancer.

Thus, the interview process helped me to redefine my ideas. I found my interests evolved as I tried to better understand what it meant to live with knowledge of genetic risk or hereditary breast/ovarian cancer. From the outset, family considerations posed a central theme in participants' responses to genetic testing and its implications. Responsibility to others figured predominantly in the reasons women cited for seeking genetic testing, as well as their responses to the test information. As the interviews progressed, I explored issues of responsibility through disclosure of test results to others. I was interested in learning to what lengths did participants go in sharing this information with others? What were their motivations for doing so? In my early writings, I linked the concept of responsibility to relational autonomy. It appeared to me that people did not pursue testing as isolated agents. Rather, their decisions reflected a choice defined and made within the context of family and community – a self in relation to others. Later, based on comparative work I did with Dr. Michael Burgess and my reading of Walker (1998), I began to explore the notion that responsibility to others is not just an obligation, but an integral part of the moral self that is manifest in many ways. Further, my very last interview with a woman of Ashkenazi Jewish descent impelled to consider a new theme: Can genetic information affect one's sense of social self, that is self in relation to ethnic or religious affiliation? This particular
consequence of genetic testing was one to which I had given very little thought until I met this particular participant. The interview also proved to be a turning point for me. It made me realize that embedded in this interview, as well as most of the accounts I heard, were conceptual issues around agency and self. This in turn provided direction for my analysis.

**Dialogical understandings**

Thus, the evolving nature of the interviews gave me a new appreciation of the complexities of genetic testing for hereditary breast/ovarian cancer and the complexity of meanings generated by this disease. It also led me to reflect on how I brought my own experiences to the interpretation of what participants told me. Here, I digress briefly to discuss my own experiences with a ‘familial’ illness. When I was 13, my mother suffered a complete emotional and mental breakdown. She never recovered and received various diagnoses including schizophrenia and manic depression (as did other relatives before her). Her treatment was (and to this day) poor and my adolescence/adulthood has been structured by moving from one mental health crisis to the next. While manic depression/schizophrenia is not considered directly inheritable, it is suspected that may be a genetic component to the mental disorder. Indeed, growing up, I greatly feared that I would get this disease. Like many of the participants with whom I talked, I was most fearful when I neared the age my mother experienced her first breakdown. I later worried about the disease affecting me when my oldest daughter reached the age I was when my mother first fell ill. After passing these milestones, I now occasionally worry about my children being susceptible. I use this example not as confessional tale, but to suggest that my understanding of hereditary illness evolved from a dialogic between my own experiences and those here. The study evoked for me a concept of re-search as I had to continuously re-examine what I learned and thought I knew,
with respect to participants' accounts, as well as my personal experiences with illness. For example, based on my own experience and what participants told me, I began to wonder whether the impact of living with hereditary cancer—or mental illness—were unique unto themselves. This is not to deny the unique aspects of the cancer experience (or mental illness) but to suggest that certain kinds of fear may be shared across hereditary illnesses. Indeed, the study led me to ponder whether it is uncertainty and emotional trauma, rather than the specific illness itself, is what brings people to desire some control. It also made me question whether it is only control of risk (or control of the "dangerous body," as Hallowell (2000: 160) puts it) that people are seeking through genetic testing and surgery.

The academic literature concentrates on notions of risk and what this means to the individual. Have we neglected to consider the converse of risk – that is, safety? Not just managing risk or putting risk in its place, but finding the zones of safety which allow us to live our lives in relative peace. Is genetic testing one of those things that permit people to broach this place of safety? Allow them to make choices that permit them to recede from the edge to a zone of greater comfort? Of course there are different realms of safety: physical safety, emotional safety, moral safety. But I think if we focus on risk alone, we may be missing something here (Field notes, April 26, 1999).

This reflection made me more attentive to how frequently participants spoke about safety. The following account helps illustrate this:

To me, it [genetic testing]'s a safety factor. I mean, if it's, if we have it, whether I have/be tested or not it's not going to make any difference. I have that gene, let's take my best chances with it. Now what can I do? I can have my ovaries removed or hysterectomy, whichever, you know, was best for me. And then your doctors know, so your doctors know what to look for. And that's the best care I can go [for].
Later, when conducting the analysis, I used the “safety” as a code to depict some participants’ experiences with genetic testing.

Participants’ accounts of genetic testing, together with various readings, also challenged me to rethink how I conceptualized ‘choice.’ Entering this study, I perceived ‘choice’ to be an uncontestable good. I saw it as a means of providing options, granting greater freedoms and providing new directions for people based on their values, beliefs and where they are situated in their lives. But through my conversations with participants, as well as various readings, I became far more aware that the language we use to describe choice is quite restrictive. I realized choice as a liberal construct often ignores the circumstances that constrain or foster people’s choices. I also thought more about the binary thinking and moral judgment embedded in choice discourse.

Barbara Kingsolver, in her book *High Tide in Tucson*, writes that in our culture we value independence and choice. Indeed, those are two notions that play again and again in bioethics. We want to give people choices, respect their choices, we view them as independent as their independence as deserving of respect. But as Kingsolver perceptively states, sometimes it is better to have no choice. It may leave someone scarred, but blameless. Choice, both as a concept and a practice, is not value-free.

One of the difficulties may be is that we tend to dichotomize choice. There are good choices and bad choices, right choices and wrong choices, difficult and easy choices. We need to open up our understanding of choice if we are to get at how choice actually works in our everyday lives. Rather than just right or wrong, good or bad choices, perhaps we could begin to think of choice in a multitude of ways. Happy, sad, surprising choices; unsettling, peaceful, ragged, clear, lucid, muddy, moody, and messy choices. In fact, our language around choice is quite impoverished (Field notes, August 1999).

As will be illustrated in Chapters 6, 7 and 8, choice – like safety – became a focal point for my ongoing analysis. These issues intersected with my exploration of identity and self.

My aim in presenting these examples is to show how empirical work is selective and positioned. I have tried to illustrate how my interaction with participants – as well as readings
-- affected my decision to pursue certain lines of inquiry over others. As will be illustrated later in the dissertation, these interactions and early reflections provided the touchstone for my ongoing analysis. I used initial interviews, as well as my own reflections, to develop a conceptual framework. I then sought to validate, refine, or reject this initial framework, as well as further enhance my understandings of research findings, through additional interviews and re-evaluation of the interviews

**Listening and telling**

Research imposes a certain order on our sense-making of experiences and relating to others, but it also creates possibilities of re-search allowing new meanings to evolve through our relationships with others. However, as Whittaker (1986) points out, inherent in every step of the research process and analysis are choices that affect the knowledge created. In the previous section, I described events, interactions and reasoning that led my pursuing certain lines of inquiry. Here, I would likely to briefly reflect on choices I made not to address other topics in this dissertation.

Unlike other diseases, which affect men and women in equal numbers, hereditary breast/ovarian cancer is almost always a female disease. Thus, I viewed gender as important to the work and the analysis. In evaluating the social and ethical questions raised by genetic testing, I saw care giving roles, personal and family relationships and patient-provider-relationships as areas requiring careful attention. Genetic testing for breast cancer (and the treatments offered) also raised specific issues for women around femininity and sexuality that needed to be taken into account. At the same time, I did not see gender as a separate factor but intersecting with other ethnic, social, economic and health determinants in influencing women’s experiences around genetic testing.
Nevertheless, the impact of knowing has consequences for women that are not experienced by men. Women, who are mutation carriers, are faced with making choices about preventive measures such as prophylactic mastectomy and/or oophorectomy. Using a feminist analysis and the consideration of relational issues, Asch and Geller (1996) ask an important question related to genetic information: “Given that breasts have value for a woman’s self-image and sex life, how might knowledge of a risk of breast cancer alter notions of self and the capacity for intimacy?” (p. 334). There is little doubt that surgical interventions pose significant consequences for woman physically, psychologically as well as socially. This particular issue was clearly evident in the research findings. Yet, as the analysis proceeded, I found myself focusing on moral identity and the relational/social aspects of self rather than the feminine or sexual self. I also chose to narrow the analysis to assessing impact of genetic information, versus the impact of procedures related to genetic testing. This is not to say that experiences of femininity or sexuality are not important to understandings of the self. Rather, this is an issue that requires intense study.

Thus, while gender analysis has played a role in my work, I have not done justice to the complexity surrounding sexual issues related to prophylactic surgery. At the same time, this issue frequently came up as part of the interview. Participants’ responses varied greatly to the surgery, demonstrating that femininity/sexuality is not just a property, but a web of interactive and relational meanings. Appendix 5 presents some interview segments to demonstrate the complexity of this issue.

A section on reflexivity, just like the data itself, involves making choices about what to include and leave out. Another area I chose not to directly address (although it is woven

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62 At the same time, I acknowledge this is an artificial distinction as the sexual self contributes to one’s identity, just as do other aspects of self.
63 This is another artificial distinction, but one that I employed to make the data more manageable.
throughout the dissertation) is the ethics of doing ethnographic research. Ethics, like choice, is involved in every step of the research process. It is embedded in choices made about setting research agendas, designing research, analysis, dissemination and subsequent use of the data (Whittaker 1999). Most importantly, it is integral to every aspect the researcher-participant relationship.

Indeed, when conducting the research, I became acutely aware that some people I spoke with were quite vulnerable and I worried about raising issues that were emotionally upsetting to them. I continually grappled with the issue: Does this research/the questions I ask cause [the participant] pain? Am I pursuing research that is respectful of their needs? Because I interviewed different people within the same family, I occasionally found myself in the position of knowing more about relatives of the person I interviewed than she. I found this an unsettling experience. At other times, the person I interviewed knew that I had spoken with other members of her/his family and would ask about those interviews. I found myself faced with the challenge of maintaining confidentiality in a situation where participants thought their questions were perfectly reasonable to ask.

The ethical problems inherent in this kind of research are profuse. But my decision not to explore these in depth reflects practical considerations, as well as the fact there are no clear solutions here. Nor do I think there should there be. I view ethics not as a set of rules or procedures, but a process. It is embedded in every relationship, research or otherwise. As researchers, we must continually ask ourselves whether our research, interpretations and writings do harm to our participants or violate them in any way. I strongly believe, however, the answer to this question cannot be found in simple codes that define ethical conduct or in an informed consent document. Rather, it requires ongoing engagement, continual reflexivity
and genuine concern for the rights and welfare of each participant. As Held (1993) has so articulately stated, ethics and morality are not a matter of knowledge alone. Moral inquiry involves living our lives and actively shaping our relationships with others, rather than just theorizing about what is the right thing to do.

Summary

In this chapter, I presented the rationale for using an ethnographic approach in my dissertation research. I also described briefly some of the re-conceptualization that occurred due to the interactive nature of the research process. In sum, interviews were held with 53 participants, of whom 39 had undergone genetic testing for hereditary breast/ovarian cancer. The interviews serve (together with field notes and participant observation) as the foundation for the findings presented in Chapters Five, Six and Seven.

In closing, however, I wish to emphasize that just as scientific models tend to simplify the world, so does the written text. Experience is more complex, more multi-faceted than anything we can write. By tending to certain meanings over others, research will always fail to consider some people’s perspectives. However, to say that our findings can never fully account for the complexity of identity and voice does not imply to me that we cannot describe social phenomena in a thoughtful manner. I have long abandoned the notion of finding a single ‘truth,’ but still believe, as Olesen so clearly articulates, that research for women is possible through “qualitative modes and theoretical writings, imperfect and transitory as they may be” (1994: 169).
CHAPTER FIVE:
Narratives in Context

There’s no absence, if there remains even the memory of absence...If one no longer has land but has the memory of land, then one can make a map.

--- Anne Michaels, *Fugitive Pieces*

Introduction

In *The Spirit Catches You and You Fall Down*, Ann Fadiman tells the story of a young Hmong student who was assigned a five-minute oral report for his intermediate French Class. He chose as his topic a Hmong recipe for Fish Soup: Soupe de Poisson. This was no simple task. “To prepare Fish Soup, he said, you must have a fish, and in order to have a fish, you have to go fishing. And in order to go fishing, you need a hook, and in order to choose the right hook, you need to know whether the fish you are fishing for lives in fresh or salt water, how big it is, and what shape its mouth is” (Fadiman 1997:12). Continuing along these lines for forty-five minutes, the student filled the blackboard with a branching tree of factors and options, written in French and Hmong. He also told several tales about his own fishing experiences. He concluded with a description of how to clean different kinds of fish, how to cut them up and lastly, how to cook them in broths flavored with various herbs. When the class ended, “he told the other students that he hoped he had provided enough information and he wish them good luck in preparing Fish Soup in the Hmong manner” (1997:12).

Fadiman uses this story to illustrate what she considers to be fundamental to Hmong identity. Hmong oral narratives tend to be long and elaborate, she explains, as they are based on the notion that “the world is full of things that may not seem to be connected but actually
are; that no event occurs in isolation; that you can miss a lot by sticking to the point” (p.13).

Indeed, the Hmong have a phrase that often comes before the telling of a story, *hais cuaj kaum txub*. It means “to speak of all things.” It is based on the recognition that a story, or any narrative, is a multifaceted project shaped by tradition, history as well as individual subjectivities and experiences.

Fadiman’s observations remind me that people come to genetic testing with complex stories, family histories and knowledge of the disease. The decision to undergo testing is not made in isolation, but influenced by a complex mix of familial, cultural and social life experiences. Understanding participant’s decision-making around genetic testing requires that we attend to these experiences. In this chapter, I seek to contextualize genetic decision-making in people’s experiences and constructions of cancer. Here, I explore the role that personal and family history plays in shaping knowing, and hence knowledge, about breast/ovarian cancer. I begin with participants’ accounts of their family history of breast/ovarian cancer: when they were first made aware of the disease, how they came to know it and how they view cancer in their lives and family. These experiential accounts then serve as the basis for examining constructions of risk identity; that is participants’ personal constructions of cancer risk or how cancer might affect them. I argue that experience with cancer leads to certain kinds of knowledge, which in turn contributes to and shapes self-identity regarding cancer risk. As Code (1993) so aptly states, knowledge is not just an abstract product based on rationality and objective determination of truth, but is a process that emerges and is shaped by the identity, circumstances and interests of the knower.

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64 The term ‘family’ is used in a plurality of ways. For the purpose of this study, I take family to mean those connected by biological inheritance, as well as those who share feelings associated with a family experience such as intimacy, connectedness, responsibility and obligation (Richards, 1996). When I am discussing family and family history in relation to knowledge about breast/ovarian cancer, however, I am referring to family members who share biological ties and their partners.
This chapter is divided into four sections. The first two sections describe how participants come to know cancer through different experiences. Section three examines the intersection between experiential knowledge of hereditary cancer and development of risk identity. Section four concludes by providing a summary of the findings. In presenting the interview data, I have tried to remain true to the participants' intent by editing their words as little as possible and by including enough interview and background data for the reader to be able to get a sense of participants' stories in context. As well, I sometimes return to the same transcript segment for different aspects of the analysis.

**Beginnings**

Even with the advent of DNA analysis, the starting point for genetic assessment begins with drawing up the family tree. Establishing biological ties among individuals, and documenting their incidence of cancer, is integral to assessing genetic risk. Counselling reflects the understanding that mothers, sisters, aunts and other family members have died from the disease. It recognizes the fear and anxiety this might engender, in particular for the individual who feels like she may share a similar fate. In the following section, I describe the different ways of coming to know cancer as a family disease. These fall under two broad categories of experiential knowledge: 1) empathetic knowing and 2) embodied knowing.

I follow Abel and Browner 's (1998) lead in characterizing 'empathetic knowledge' as knowledge derived from close associations or emotional ties with others experiencing a particular event. I further expand the concept to capture the observation that it includes knowledge of disease that draws on biological connections to others, with whom one has or has not had contact. Empathetic knowledge enables individuals to give authority to their own understanding of disease, which has been generated by connectedness to and knowledge of
other family members experiences. Embodied knowledge, on the other hand, refers to subjective knowledge derived from experience (Abel and Browner 1998), in this case, of having cancer oneself. In the context of hereditary cancer, however, it is important to note the impossibility of completely disentangling these two kinds of experiential knowledge. For example, a woman might come to know cancer through a relative’s experience as well as having the disease herself (empathetic and embodied knowledge). Thus, perceptions of risk for future disease are grounded in personal illness as well as connectedness to others who have had the disease. I do not use these categories to set limitations on knowing, but to provide an orientation and understanding of the complex ways in which cancer is experienced and may come to be known in the family. This focus also lays the groundwork to consider how experience and knowledge of hereditary cancer influences notions of risk and self-identity.

**Empathetic Knowledge**

Empathetic knowing appeared to exist along a continuum from weakly held to strongly held convictions based on close ties with others. In order to describe this further, my construction of empathetic knowledge is divided into four broad explanatory patterns: tangible knowing, recent knowing, distant knowing and accidental knowing. Tangible knowing refers to subjective knowledge derived from close associations and personal experiences with people suffering from breast/ovarian cancer. It also includes strong awareness of the family history of the disease. Recent knowing is also derived from observing the experiences of others, but refers to cancer (and thus knowledge of cancer) as something new to the family. Distant knowing refers to knowledge of familial cancer obtained solely through discussion and stories about other family members. ‘Accidental
knowing' signifies knowledge of familial cancer obtained by chance. I now explore each of these in turn.

**Tangible Knowing**

Of the 53 participants, over two-thirds (n=39) came to genetic testing aware of their strong family history of the disease. This was obtained in different ways. For the majority of participants, however, these histories included living with someone with breast cancer or witnessing the death of relatives. Lorraine’s story is typical in this regard.

My Auntie P, who married my dad’s brother, was the first one in that family to get diagnosed with cancer and she died of breast cancer at the age of 37. Then, the next sister was Auntie F. She had breast and ovarian cancer, I believe, and she was forty-seven. Then mom’s younger brother, Uncle J. got diagnosed with a brain tumor, and he was about age 50 when he died. So it always seemed like we were going to funerals and people were sick when I was a kid growing up...And then about five years ago now, my mother, well she died about five years ago, but she was diagnosed six years before she died with ovarian cancer. So she had surgery, and then she had chemo, and then she had chemo again...I took time off work and looked after her for about three months with my father. She died at home.

Several times during our interview Lorraine recollected how cancer was part and parcel of her childhood.

I mean I remember that as a kid thinking you know, who’s next? When does this ever stop? And I had friends in school who you know when we were getting into high school and that we talked about things and they had never been to a funeral and it’s like you’ve never been to a funeral? I mean we go all the time. It used to seem like that.

Indeed, many participants had difficulty in distinguishing clearly the age at which they first learned about the existence of cancer in the family. It was just something that was always there. One of Barbara’s earliest childhood memories was waiting in a car outside a hospital while her father visited his sister. Her aunt was being treated for breast cancer and died soon after at age 31. A few years later another aunt died of breast cancer and when Barbara was in her twenties, several cousins were diagnosed with the disease. Then one of
her twin sisters developed breast cancer when she was 39 years old. She died three years later and her second twin sister developed cancer one year after that. This sister fortunately has just reached the ‘five-year’ survival mark.

Brenda, who is now in her late 40s, recounts a similar history. Although she did not think about it much as a child, she had an awareness of the disease as being part of the family legacy. Her family linked her to a particular past, present and future in which cancer played a central role.

I had like three or four aunts die of cancer when I was really quite young. I remember that they were sick. I didn’t really fully understand what cancer was but I knew that was why they were dying. And then, um, so, at a very young age we knew that there was cancer, a lot of cancer in our family. And then when my mom, um, got cancer, uh, then it was really close to home. My sister had cancer in her breasts ...when she was thirty... And then my, more recently, my cousin passed away and it was, uh, she started with breast cancer and another cousin got breast cancer. And it was just everywhere. Everywhere we looked it was so prevalent. So [I’ve been] very aware of it since a very young age.

In addition to being aware of their family cancer history at an early age, many of the women interviewed had provided care for mothers or other family members who had the disease. These women drew on experiences of caring for others to construct knowledge about breast cancer and the course it might take in their lives. In fact, much of the literature suggests that these experiences are a source of prolonged anxiety (Chalmers and Thomson 1996; Chalmers, Thomson et al. 1996; Murphy 1999; Rees, Fry et al. 2001). Perceptions of risk are influenced and intensified by experiences of cancer with particular family members. Chalmers and Thomson (1996) also observed that variability of the illness trajectory influences how people caring for those with breast cancer perceive the illness. Those who witnessed unpredictable or erratic illness paths often saw cancer as a greater threat to themselves, and others, than those who experienced a more linear path. This study revealed
similar findings. The more complex the trajectory path, the more difficult the lived experiences became. The challenges of a complex path are reflected in Nancy’s words. She was in her twenties when her older sister was first diagnosed with cancer. Her mother developed ovarian cancer soon after and struggled with a difficult course.

I think my sister was the first to have cancer that I knew of. I think she was about thirty-two at that point and it was really scary...And then mom got cancer. She was like my best friend and it was to hard to take, I guess because I was there everyday for three years...The worse thing was your hopes going up and then getting crushed. Like they always gave you good news and it was always followed by bad news, you know. So for three years, it was just the yo-yo, you know, the emotional yo-yo.

She went into the coma like four days before she died, so she really was aware of everything. And sort of the way they treated her / like she mom would say I know you’re waiting for me to hurry up and die to the nurses / like the anger, I guess, the shock when they told her like she had six months. I don’t know. I guess it’s funny, but I had dreams about that, about her cancer coming back. She walked through the Cancer Clinic door the second time and I knew she had it back before her and the doctor did. I had dreamed that and oh it was terrible. I had so many dreams during the whole time / three years of just all the fear and everything and not knowing what was going to happen. But like I said it was the hope and the disappointment after the hope that was so hard to take.

Vicki also talked about the difficulty of watching her mother suffer from ovarian cancer and get progressively worse over time. This was made more difficult by the fact that Vicki had breast cancer 10 years earlier and remained cancer-free since then.

Mom died of cancer at fifty-six you know. So she kept believing that the Lord was going to heal her like he did me, but it never happened and it was really hard watching my mom go through this just a few years after I had gone [through it] ... It was I think like five years or something after I had it. She had ovarian cancer and then she fought it for a long long time and then she just gave up. I saw her.

Many of the caregivers came to know cancer as an illness that is painful and full of suffering. Anna described her experience in this way:

My maternal grandmother died of breast cancer...she died in 1972 of breast cancer that was basically untreated. She had a mastectomy. I don’t think there was any other treatment. She had a hideous, hideous death. She was paralyzed from the waist down, it went to her spine, she died in agony ....My mother got breast cancer when she was
68 and we were just sick. I had no picture ever of anyone surviving breast cancer ...so mom got breast cancer and it went from bad to worse. She had bad treatment, I think partly because her doctor saw her as, you know, as she was 68, she's old, which is, you know, nothing and she was scared to have chemo, so she didn't. She tried taking [alternative medicine], and stuff like that, went to the other breast, she got parotid gland cancer and her face was all twisted up. It was horrible. And then she had lung cancer and liver cancer. [But] she died actually very very peacefully in my arms at the hospital.

It is important to point out, though, that not everyone's experience with breast cancer was so grim. Sheila's mother was afflicted with breast cancer at age 44 and her sister at 36. She also had an aunt who died of ovarian cancer. While she feels that she is at high risk for developing cancer, for Sheila the disease does not represent such a horrible fate. At the time of our interview, Sheila was 36 years of age.

We got excellent survival with my mom and with my sister and if I get breast cancer it's going to be dealt with the same way as my sister did. It's going to be an incredible inconvenience for four to six months and then it's done.

As the preceding passages suggest, the kinds and intensity of lived experiences shaped the manner in which participants came to know and understand cancer. The experience of watching and caring for relatives with cancer had strong impact on how they perceived the disease. Illness trajectories that were unpredictable, or characterized by long periods of suffering and incapacitation, demanded ongoing emotional adjustment for relatives and others caring for them. They were highly stressful times for the caregivers and often marked by anxiety and fear. This observation is supported by literature which shows that family members often experience as much psychological distress as the affected individual (Baider and De-Nour 2000; Weihs and Reis 2000). Different levels of experiences contributed to different levels of knowing. Moreover, these experiences may be more stressful if a person attending to the relative is aware of her own risk of developing the disease (Rees, Fry et al. 2001) and in turn contribute to a greater fear of cancer.
In addition to the number of affected relatives, other participants’ recollections were shaped by what they perceived as the relentless progression of the disease trajectory. Gillian’s initial awareness of cancer began with her mother’s diagnosis of breast cancer, although she did not think of it as a family disease until both her aunt and sister were diagnosed with breast cancer several years later. Her mother’s first cancer was treated with a lumpectomy. Several years later, however, she developed breast cancer in her other breast. She elected to have a double mastectomy at which time a third cancer was found behind the lumpectomy scar. This was quickly followed by two episodes of ovarian cancer. As a result of observing her mother, Gillian views cancer as a disease that is unyielding. Her mother’s experience has also made her concerned about her own risk.

I was just really scared because I thought, gees, it is so relentless. You know, this cancer is just, won’t go away. …I was just really scared for her, but also, like, angry, you know, why, why it just won’t stop. And also then I, I got nervous about myself like, you know, what my risks were. They’re pretty high.

As this comment suggests, Gillian drew on her mother’s experiences to construct knowledge about cancer. Cancer became a very real threat not only to her mother, but to herself as well. She incorporated her mother’s experiences into her own evolving sense of risk and self-identity. As Elliott (1999) observes, “Illness and health, disability and difference, cure and enhancement: it is a mistake to think there can be rigid distinctions here. This is because illness, health, disability and difference all are connected to a person’s identity, her sense of who she is” (p. 48).

Marlee also talked about the relentlessness of cancer in her mother’s life. She was seven when her mother was first diagnosed with breast cancer and the disease has been a backdrop to her life ever since.
[My mother] was thirty-seven when she was first diagnosed with breast cancer, and since then it's been ongoing... Five years later she got ovarian cancer and we thought we were going to lose her. They said she wasn't going to live. I was very close to my mom, very close, and so it was hard. ... Like I said, it's just been ongoing. She's had ovarian/ I think three or four times it's recurred and the breast cancer, and then she had [cancer] in her lymph nodes in her neck. And of course scares along the way so it's been very emotional and up and down.

At the time of our interview, Marlee's mother was doing well at 64 years of age. Nonetheless, Marlee's comments again bring to bear the emotional difficulty of watching a loved one suffer the consequences of an unpredictable disease. Not only does this contribute to an individual's knowledge about cancer, but it is likely to have a profound effect on how she perceives cancer in her own life. Just as knowledge of other family members contributes to one's own identity, so might the familial nature of a disease. As will be discussed in more detail, one's sense of future self might include fatalistic notions of the disease.

Other ways of knowing

The previous accounts described thus far show how individuals' knowledge of familial breast/ovarian cancer is shaped by family patterns of inheritance, personal observation and the experience of caring for others. The proportion of family members affected by breast cancer, loss of relatives as well the number of times it occurred in one individual, also contribute to understandings of the disease. While the vast majority of participants had close or frequent contact with someone who had the disease, a small minority came to know cancer and their family history of cancer as a recent event or through less direct means. I differentiate these experiences as recent knowing (n=11), distant knowing (n=2) and accidental knowing (n=1).
Recent knowing

The extent to which individuals are aware of hereditary conditions depends not only on communication within the family, but also on the temporal course of cancer within the family [Richards, 1996 # 83]. Indeed, for Kate, knowledge that cancer ‘ran in the family’ was a new discovery. Up until her generation, the family apparently had been cancer-free. Both her mother and father, although elderly, were in relatively good health. Grandparents and older relatives had died of unknown or unrelated causes. There was no documented diagnosis of breast cancer in either immediate or extended family. Thus, the issue of hereditary risk did not arise until two of her four sisters developed breast cancer. Her older sister was diagnosed with breast cancer at the age of 43 and her younger sister at age 39. Kate was in her early forties at the time.

Oh, I must say, I really didn’t think that much about it when Margaret was diagnosed, but when Kim was diagnosed, like the first thing that comes to your mind is WHO’S NEXT?... I think probably all the girls in the family sort of said to themselves, ‘HOLY SHIT, YOU KNOW WHAT IS HAPPENING HERE?’

Recent knowing overlaps with tangible knowing in that both are derived from experiences with particular others. Yet, in comparison to those who described cancer as something that was always there, the latter example illustrates knowledge of cancer as something new to the family. “Families link us to a particular past and a particular future” (Nelson and Nelson 1995: p. 42) and play a central role in shaping knowledge of certain things. Up until her sisters’ diagnoses, Kate attached no meaning to cancer other than it was a frightening, life-threatening disease. Her sisters’ illnesses impelled her to re-evaluate the implications of the disease for her family. Because of their experiences, she began to question the place that cancer might have in her own life and the lives of other family members. Thus Kate, like

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65 I use capitalization to reflect the emphasis the participant placed on certain words.
other participants, turned to subjective experience and family history of cancer (past, present and ongoing) in constructing her knowledge of cancer, cancer as a family illness and personal risk identity. Media reports and her job as a lab technician in a local hospital also supplemented the development of her ongoing knowledge.

Distant knowing

For a few women, familial histories of cancer were distant and known solely through family discussions. Indeed, Marilyn was typical of those who recalled having an early, but less tangible, knowledge of her family’s history of cancer. Her grandmother had died from breast cancer at a young age, long before Marilyn was born. She had also been told that two aunts had died from breast and ovarian cancer, but did not know either of them personally. Never having lived with someone who had breast or ovarian cancer, she felt removed from the familial cancer experience. Nonetheless, Marilyn like many participants feared cancer. She drew on popular discourse and social representations of cancer to construct her beliefs about the disease.\(^{66}\) She did not view it as benign.

I don’t know I’ve always been scared of cancer for some reason, but not because of family or anything like that, it’s just always, I probably just thought it was horrible. Like something you would never want to have. It seems like it’s all over and terrible stories about it. But no it was just a just a feeling.

Like Marilyn, Catherine was not exposed to cancer in her childhood or adolescence. Only when her father’s cousin was found to be a BRCA1 carrier and her father then pursued testing, did she begin to consider the family implications of the disease. She was in her mid-twenties at the time.

I never thought of our cancer risk in terms of all the relatives. I knew my grandmother obviously had died of breast cancer ...[but] I never connected it...I knew my Aunty E., but she had died what I understood of ovarian cancer and of course I hadn’t linked breast and ovarian cancer. I didn’t have that knowledge that there was some kind of

\(^{66}\) See Kasper and Ferguson (2000) and Potts (2000b) for a good overview of this material.
genetic link you know between the two. And I didn’t as far as my other aunties that had passed away of breast cancer, I never knew them and you know we hadn’t talked about them a lot. So I knew that there was cancer in the family. It was always something, but it never/ I didn’t understand it to be the way it you know that I understand it to be today.

Catherine’s account indicates it was genetic testing that led to her awareness of breast/ovarian cancer as a familial disease. Unlike other participants who witnessed cancer first-hand, Catherine’s exposure was remote. She knew that her grandmother and several aunts had died from the disease, but she had no personal contact with them. Cancer posed little threat to her. Only when a genetic mutation was identified in the family did their deaths – and the import of their disease -- gain much significance for her. Thus in her case, it was genetic testing that brought the family nature of the disease to the fore. Catherine’s experience points out how genetic testing may lead people to construct new understandings of cancer as well as consider their family history in new ways. It can force a re-evaluation of what was previously known. As she said, “I knew that there was cancer in the family. It was always something, but it never/ I didn’t understand it to be the way it you know that I understand it to be today.” This, in turn, had significant implications for how she interpreted her cancer risk and began to see herself. 67

Accidental knowing: learning by chance

One participant, whom I call Sara, learned of her family history purely ‘by chance.’ Her parents had divorced when she was very young and her mother had lost contact with her father’s side of the family. Long after Sara had left home, her mother met her former husband’s cousin at a local store. They recognized each other, and the cousin, who had been

67 For both these participants, transmission of the BRCA mutation came through the paternal side of the family. An issue worth examining further with further research is whether hereditary cancer is deemed more significant, or if more attention is paid to it, if it comes from the mother’s side rather than the father’s side of the family. Do we encounter more ‘distant’ knowers in the latter group?
tested for the BRCA1 mutation, told her about the program. The cousin, through Sara’s 
mother, invited Sara to participate. This was the first Sara had ever heard about either genetic 
testing or the family history of the breast and ovarian cancer. Several times during our 
interview, she spoke about how this discovery disturbed her.

The thing that was scarier I think than anything, is that you realize, look at all these 
family members that I don’t even know. I have been so removed from that side of the 
family. So that was kind of disturbing because you think it is sad in a way that you 
know we weren’t in touch with all these people, or that there wasn’t anymore 
communication....Maybe when all these people were being diagnosed because of 
some of the ages or the I think it was just overwhelming to sort of for me, to sort of 
realize that hey, there’s all these people that I am related to, all of the sudden there is 
this realization that something’s happening in the family and it could have affected 
me or could affect me. And I didn’t have a clue about it...And I do realize that 
because even with my dad and his parents and stuff there was a lack of 
communication, so I can see why it happened. But it is kind of frightening when you 
look on paper at all these people and you’re going wow, I don’t even know them.

A genetic test yields results that extend beyond the individual, affecting all members of a 
shared biological descent whether intended or not. Sara’s words suggest that her concern for 
getting cancer was made more difficult by the lack of communication with family members 
and uncertainty about her past. She lived her life divorced from these other family members 
and unaware of her family’s history of cancer. In learning about this history, Sara was 
compelled to renegotiate her identity both in terms of a new-found family and a disease for 
which she was at risk. The following passage helps illustrate how this challenged her sense of 
self.

I think it was just overwhelming for me to sort of realize that hey, there’re all these 
people that I am related to. All of a sudden there is this realization that something’s 
happening in the family and it could have affected me or could affect me. And I 
didn’t have a clue about it.
As previously stated, a person’s identity is not formed in isolation but within a certain family, culture and history. One’s sense of self and risk identity is connected to the experiences with and knowledge of others.

**Embodied knowledge**

While the previous group of women used family history, the experiences of caring for others, family stories and media representations to construct their understandings of cancer, others also drew on embodied knowledge. In using this term, I refer to Browner and Press’s (1996) study of pregnant women in which they characterized embodied knowledge as “knowledge derived from a woman’s perception of her body and its natural processes.” Here, I take embodied knowledge to mean knowledge gained from subjective experiences with cancer and cancer treatment. This group is distinguished from the other participants by having had cancer already and by being patients themselves. Yet, there is frequently overlap between the two.

Indeed, of the 34 female participants who elected to have genetic testing, fourteen had been previously afflicted with breast cancer. Because of their family histories, many were not surprised when they received their diagnosis. Some, in fact, lived their lives thinking that cancer was inevitable. As Ellen, who was in the terminal phases of her illness, put it: “I think always in the back of my mind, I would either go with a heart attack from my father’s side of the family or with cancer from my mother’s side.” Marlee expressed similar sentiments, although she did not expect to develop breast cancer at such a young age.

I was diagnosed at thirty-three, just before I turned thirty-four with breast cancer. And I guess I always thought I was going to get it. Just because I’m so much like my mom I always thought I’d have to face it one day, but not so young.

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68 The number is even larger with respect to the whole group. In the study, there were 45 female participants of whom 17 had experienced breast cancer.
Not everyone, however, was prepared for getting the disease. Despite her family history and Ashkenazi Jewish ancestry, Martha described her diagnosis of breast cancer (at age 50) as a total shock. As Martha put it:

I didn’t think about it [cancer] because I was fifty and I felt I was too young. My aunt had had breast cancer when she was in her eighties. When she was critically ill with other things, they found breast cancer. My mother had breast cancer diagnosed when she was sixty-one. Because I’m a nurse, I’m aware, probably more aware of statistics than the general population of women. I know that there would/there is an increasing risk of me developing it as I got older. I thought it would be something that, that I would most possibly develop, but not at fifty. I thought this would be a health challenge when I was old.

As this comment indicates, Martha drew upon both the biomedical model (cancer is a disease of older women) as well as her family history to construct her knowledge of cancer. Her experiences -- personal as well as professional-- led her to believe that she did not have to worry about breast cancer until she reached a later age. Nonetheless, her embodied experience caused her to reinterpret her understanding and knowledge of cancer. This shift in understanding also raised new concerns about the implications of cancer for other family members. As Martha put it,

One of the things that was really concerning me, because I had not considered myself as a ‘breast cancer victim’, uh, was my family. Because all of a sudden, now knowing that I had breast cancer, my mother had breast cancer and her sister, I felt that our family was at risk. And so I was worried, really worried for my sister and my niece.

Although from a different family, Ingrid’s story bears strong similarities to Martha’s. Her mother died of Alzheimer’s disease and her father of ‘old age.’ Her own diagnosis of breast cancer at age 37 came as quite a shock. Further, five years later she developed ovarian cancer, which recurred twice. But it was only when her daughter was diagnosed with breast cancer at age 33 did she begin to think of cancer as a family disease, with implications for her daughters, grand-daughters and future generations to come. Thus, in comparison to others
who described cancer as inevitable, or occurring in a specific ways, the latter examples illustrate an evolving or changing knowledge of cancer. Martha and Ingrid’s daughter’s diagnoses forced them to re-evaluate the familial implications of the disease. It was through their concrete experiences that new knowledge and a new sense of what breast cancer signified began to emerge.

In looking at meanings around Huntington disease, Nancy Wexler (1979) found that HD imposes a burden of anticipation and silent apprehension. Hereditary cancer seems to involve a similar burden. There exists a burden of anticipation based on the family legacy of breast cancer. As the preceding accounts suggest this is shaped to various degrees by one’s experiential knowledge and connectedness to others who have had the disease. But the burden of anticipation in breast/ovarian cancer may also be based on one’s personal, ‘embodied’ experiences. Indeed, affected individuals often recalled their personal cancer experience (diagnosis, surgery and adjuvant therapy) when constructing their knowledge of cancer. Recurrence raised particular concern. Margaret discussed this aspect of cancer several times during our interview. She had had breast cancer at age 43, four years before our interview:

[C]ancer is one of those things. It is not like getting your appendix out and six weeks later you go down the road. Cancer is something that’s just always niggling there. Every time you have to go through a check-up you get, you work yourself into a frenzy. Every time you have got to go back to that cancer floor, you sort get you sort of get this antsy feeling in your stomach that, Oh, do I have to do this again? So, you know there was some apprehension, but mostly it came around times of appointments or blood tests or things that sort of triggered it.

I think that’s the other thing people don’t understand cancer’s something that you never stop living with. It’s not like getting your gall bladder out and six weeks later your just back on the mend. Cancer’s just always there.
Margaret’s comments illustrate the challenge of living with a life-threatening disease for which there is no cure. Cancer unfolds with a rhythm of its own to which the person must adjust. Her fear ebbed and flowed often intensifying around the time of medical check-ups. She did not view as a one-time-disruption to her life, but as a threat that was always there. The uncertainty of cancer and fear of recurrence is not unique to familial cancer, however, but a frequently documented concern of cancer survivors (Shanfeld 1980; Mishel 1988; Oktay and Walter; Nelson 1996; Steginga, Occipinti et al. 1998). Uncertainty exists when the probability of outcomes is unknown (Bottorff, Ratner et al. 1996).

Participants’ embodied knowledge also revealed the very real consequences of having the disease. This began with the diagnosis of breast cancer. Some participants found the lump themselves. For others, detection occurred during a clinical exam and for others still, by mammography. Embodied knowledge was then influenced by disease extent (localized disease versus lymph node involvement) and the effect of cancer therapy on women’s bodies. Indeed, women reported diverse physiologic responses to their cancer and cancer treatment. Overall, however, surgery (i.e. lumpectomy or mastectomy) did not seem to pose as much of a physical challenge to participants as did chemotherapy and radiation treatment.69

Margaret, for example, spoke at length about chemotherapy in describing her cancer experience. She elected to have mastectomy after a malignant lesion was found in her breast. This was followed by four regimens of chemotherapy from which she suffered horrendous side-effects. She vomited every two hours for about four days after each treatment. It also

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69 Although the role played by ‘breasts’ in the construction of gender identity is not straightforward, many participants referred to the impact of surgery and breast loss on their sexuality and perceptions of femininity. The literature on this aspect of breast cancer is extensive and it suggests that breast cancer, more than other cancers, is especially culturally laden because of the ways in which femininity is located in the female body (Sawyell et al, 2000). The results from my study do not add anything new to this discourse. Thus I decided not to include this aspect of the research here.
threw her into instant menopause. She felt completely drained of energy. "It was just an effort to do anything." But most troubling to Margaret was the lymphedema resulting from the axillary node surgery. She says this has had a significant impact on her life.

I have had a fair bit of trouble with is lymphedema...and I have to watch what I do. And my quality of life has somewhat changed. I mean I used to be the one that mowed the lawn and we used to have a huge garden where that camper sits right to the back here. And I remember coming home from physio and saying to [my husband] that the physiotherapist said like I shouldn't be doing that hard of work with my lymphedema and the heat. So we planted cement. That was a little hard to take you know and things like. It’s definitely changed some of my life style.

For Margaret then, her ongoing difficulty with lymphedema caused her to give up something she dearly loved to do. In addition to the personal trauma of having cancer (and its threat to her future), she has had to change her lifestyle based on her physical abilities. Cancer and the iatrogenic effects of treatment forced a re-negotiation of her self-identity. Similar to other studies in the breast cancer literature (Potts 2000; Saywell, Beattie et al. 2000), some women talked about hair loss (following chemotherapy) as being a direct challenge to their experience of self. Although it was only temporary, Laura referred to hair loss as especially difficult for her. It represented the most visible manifestation of having cancer and was an affront to her identity.

What I found the most difficult was the loss of hair you know. You are talking eyebrows, eyelashes so basically you look very alien to yourself, right? So there’s lots to deal with, you know, your physical appearance has changed so much.

While nausea, vomiting and hair loss were frequent outcomes of chemotherapy and fatigue with radiation, most women faced with breast or ovarian cancer talked about their treatments as something they just had to get through. As Ingrid put it: "[It] was no picnic.

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70 Whether a woman has lumpectomy or mastectomy, a sample of lymph nodes is usually removed to ascertain whether the cancer has spread. A complication of this procedure is lymphedema, swelling of the arm. This occurs as a result of cutting lymph and blood vessels during surgery and excess lymph fluid accumulates in the arm (Oktay and Walter, 1991).
but then you think well I'll get over it and go on. That's all you can do." Some women experienced fewer side-effects from their cancer treatments and continued to lead active lives. Kim, who had been diagnosed with a cancerous tumor and minor lymph node involvement for example, said that she felt exhausted after chemotherapy but never terribly ill. She attributed her response, in part, to a perceived need to appear well for her three young children.

I only had four chemo's -- every three weeks -- and the last one I was sick... But you know I didn't want my kids seeing me lying on the couch sicker than a dog and so I think that had something to do with it. I mean my mom would bring me soup and I had a hard time eating, but no, I found it not bad at all.

Although treatment was experienced physiologically in different ways by the women afflicted, the comments above speak to how the physical reality of the body is integral to daily life, agency and self-identity. For many participants, their sense of self was challenged by cancer treatments. Further, as the work of Mathieson (1995) and Luker et al. (1996) has shown, cancer can remove individuals from their social roles and activities (family, work social life). For many women, this has profound implications on the way they conceive their selves and their bodies, as well as their selves as embodied (Hallowell 2000). Cancer, as understood as a life-threatening disease and known through particular physical experiences, tended to force a re-negotiation of agency and self-identity. Embodied knowledge came from different ways of living with or knowing breast cancer in particular ways. Beyond this, embodied knowledge can also be set within the context of the family’s broader story (past and ongoing).

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71Once again, the literature on this aspect of cancer is vast. See Lupton (1994), Luker et al (1996), Rosenbaum and Roos (2000) and Potts (2000b) for more recent discussions.
From Cancer Knowledge to Risk Identity

In the previous sections, I discussed knowledge of cancer that arose from family and personal experience with the disease. Moreover, many participants articulated an embodied knowledge of cancer that was linked to family history. It gained further significance from what had gone before it and what it implied for the future. Recall Ellen’s words: “I think always in the back of my mind, I would either go with a heart attack from my father’s side of the family or with cancer from my mother’s side.” Knowledge of cancer arose from personal experience as well as the course it had taken in other family members’ lives. Subjective experiences as well as the experiences of kin were integrated into their knowledge claims.72

In this section, I examine the relationship between various experiences with cancer and constructions of personal cancer risk. Watching loved ones suffer from an unpredictable disease not only shapes an individual’s knowledge about cancer, but can have a profound effect on how she perceives cancer in her own life and the lives of other family members. As previously stated, for many women in this study, cancer evoked a common story and shared identity that connected the individual self to others. Perceptions of risk for future disease were grounded in personal illness as well as the experience of others. This knowledge of shared identity also had implications about cancer risk for daughters, granddaughters and future family. Without exception, all parents afflicted with breast/ovarian cancer expressed concern that their children were now at increased risk. Concern was frequently raised about risk for siblings and other family members as well. In Margaret’s words:

72 “While it is widely accepted as a truism in all sorts of contemporary discourses that we are changed by life-threatening events, the new sense of self is not necessarily either outside or prior, nor more authentic, than the alternative or previous identities. The text brings together all the different selves around the unfolding story of the disease” (Potts, 2000: 116). To this, I would just like to add that although I write about cancer as affecting participants’ sense of self or self-identity, I do not see identity as fixed. It refers more to the process of becoming and incorporating difference senses of being. In other words, identity is in a constant state of flux.
I am scared for them. I don’t want them to have to go through what I went through. I really don’t want them to have to have cancer. I don’t want them to have to go through all the chemotherapy and all the horrendous experience that it causes.

Similarly, Anna spoke about the traumatic legacy she has left her daughter.

You know, my daughter said to me -- this is the saddest thing -- my daughter said to me “mom it seems like one woman in every generation of our family dies of breast cancer, and I’m the only woman in this generation, so I guess it will be me.” So, you know, this picture of my grandmother, to my mother, to me, to [my daughter], was like “oh, God!”

Participants who were cancer-free also drew on the experiences of other family members to construct perceptions of whether or how cancer might affect them. Just as their knowledge of breast cancer was shaped by family history and caring for loved ones with the disease, so too were their beliefs about personal cancer risk. Participants used their experiential knowledge as a basis for constructing risk identities. Vulnerabilities were triggered by knowledge gained through connectedness to others and by personalizing life experiences of family members affected by the disease. For example, following her mother’s death and sister’s diagnosis of breast cancer, Nancy began to worry excessively about her own risk. She asked her doctor for monthly clinical breast exams. She checked herself compulsively – at least once and sometimes more over the course of a day -- for breast lumps. As she watched her sister deal with the ill effects of chemotherapy, she decided to have prophylactic surgery. Fear of cancer began to overwhelm her life.

When [my sister] got cancer that was so tough. She was at work with me and watching her hair come out and what she was going through was so hard to take. That made me decide that while I had all my strength, I was going to do anything I could and remove any part of my body that I HAD TO and have the STRENGTH TO FIGHT and get better after the surgeries than [go] what she went through with no strength left after chemotherapy. It just drained her.

I was that deathly afraid of getting it. [After] watching [my sister] struggle with all of that in her body, all the chemicals and trying to fight to stay strong it was kind of / it’s too much that.
Similarly, Jan’s fear of breast cancer was grounded in the experience and knowledge of others. From the time she could remember, her mother was worried about dying from breast cancer. Her grandmother, two aunts and a number of cousins had struggled with and/or died from the disease. Jan had chided her mother about her concerns. She told her just to live her life and stop worrying about developing the disease. Eventually, however, Jan’s mother was found to have breast cancer. At this point, Jan realized the amount of anxiety she herself harboured about the disease and how vulnerable she felt. Her mother’s fear had become her own.

There were a couple of my friends who also had got a diagnosis of breast cancer around the same time. And a friend my age who died of AIDS, which was of course not the same thing, but a woman I knew well dying young. I began to imagine I had a lump. And I thought this is exactly what I told my mother not to do. And I could kind of visualize it growing in my left breast and I knew that wasn’t a smart thing to do. So I went to a therapist I knew... that helped a lot and I would say I stopped obsessing about it, but it probably remained an underlying concern and maybe even a conviction that like my mother, I decided that was how I would die.

Jan’s comments illustrate that the knowledge she gained from direct experience came not only from the family, but from close friends struggling with illness as well. Nonetheless, she too became convinced that she would get cancer and that it would eventually claim her life. She envisioned her death to be the same as her mother’s.

Others approached their family legacy with far less fear. Sheila, for instance, recognized that she was at high risk for breast cancer. Her mother, sister and other relatives had the disease. In contrast to participants who witnessed the devastation of progressive breast cancer, however, Sheila’s knowledge of breast cancer was shaped by a mother and sister who responded well to treatment. Thus Sheila, like the other participants, emphasized subjective experience and family history of cancer (past, present and ongoing) in
constructing her knowledge and personal risk identity. Yet, as the following quotes illustrate, she does not struggle with thoughts and emotions about death but sees a possibility of control. Based on her family history, she holds hope for the future even though she thinks her chances of developing cancer are very high.

If I were to be diagnosed with breast cancer tomorrow, not a whole lot would change. We would deal with it. We would be inconvenienced and hopefully I would end up with more hair than I have now (laughter), but that’s it.

I’m not shutting my eyes. I am already assuming that I am in the ninety percent [risk category]. It’s not weighing me down because I won’t / it’s not in me to have that happen. I got too much living to do to worry about dying.

While the threat of cancer does not dominate her thoughts, Carolyn recognized that she was at risk at a relatively young age.

I think when I started getting breasts myself, that’s when it, you know, you realize that they’re there but they’re not permanent, you know what I mean? They’re, they’re not invincible. So I started giving myself breast examinations when I was quite young [15 years old].

Disease that is passed from generation to generation bears an enormous familial significance. It creates distinctive vulnerabilities that arise from being part of this group. Women who resembled mothers, sisters or other relatives afflicted with breast or ovarian felt especially vulnerable about getting the disease. Those who shared physiological traits, in particular, thought they might follow a similar life course. As Marlee stated previously: “Just because I’m so much like my mom I always thought I’d have to face it one day.” Her sister made a similar observation.

Because she’s so much like my mother, you know ... I was shocked, but really not surprised. I knew one day in her life she would get it. I thought she’d get it and sure enough she did.

This finding is in accord with previous work that suggests lay concepts of inheritance are often based on resemblance, not only physical characteristics but personality traits as well
(Hallowell, 1999; Richards, 1996). “Family members try to make sense of the pattern of occurrence of the disorder they observe in their family in terms of previously held knowledge about inheritance” (Richards, 1996: 267). Comparing self to other family members is important to ascribing risk. It is underscored by notions of heredity and biological inheritance. Those who resemble affected relatives are likely to be seen at increased risk and those who differ are considered less vulnerable. Individuals at risk for Huntington disease also refer to the degree of resemblance (both physical and behavioral) when constructing their risk of developing the disorder (Cox, 2003; Richards, 1996). Their beliefs about risk often persisted even after contradictory scientific accounts of inheritance are provided (Richards, 1996). Similarly, investigators found that 61% of women with a family history of breast cancer, who overestimated their risk, continued to do so following genetic counselling (Watson, Lloyd et al. 1996). Obviously, family history plays an enormous part in the construction of personal risk even as scientific knowledge shapes that construction.

In addition to family resemblance, the age at which close family members were first diagnosed with cancer acquired particular salience for some participants. They worried more and their sense of vulnerability increased as they neared the age when others in their family developed cancer. Susan spoke about this several times during our interview.

It was something that I always thought about. I was always concerned and I guess I felt that I’m creeping up to the age where she [mother] got it.

I never really told a lot of people that I worried about it, but I did tell my doctor you know and that's/ I think of the point where I finally told the doctor is I was really getting worried and because I was coming up to thirty and that's when when it all had happened for my mom as well, so that really really scared me. I just wanted to know if there was something I could do or you know because of the history in my family. Does that mean I'm going to get it? This is what I was asking him.
Nancy expressed a similar kind of fear. Her two sisters both had breast cancer, at age 30 and 41 respectively. She underwent prophylactic surgery (both mastectomy and oophorectomy) at age 40 because she was convinced that she'd develop cancer within the year. Interestingly, this sense of vulnerability was not held exclusively by women. Although male participants did not fear breast or ovarian cancer per se, they did express concern about developing some form of cancer around the same age that a close relative had it. Ross was 14 years old when his mother died of breast cancer. When I asked him whether he ever worried about getting cancer himself, he put it this way:

My mom was sick was for quite a while but played quite an important role in our lives when we were younger. And there is probably hardly a day that goes by that you don’t think about her...I guess you asked the question did I worry about it at times? Well I guess the period of worrying about it was when my children were young and I was the age of my mother when she died and thinking you know God, what she went through with three boys and knowing that she was dying of cancer. Like I guess that is a time where you start to worry about it you know, like a little bit. [But] that period passed.

Several other studies also indicate that individuals' feelings of susceptibility to familial cancer are heightened as they approach the age at which a close relative was diagnosed or died from the disease (Richards, Hallowell et al. 1995; Chalmers and Thomson 1996; Brain, Gray et al. 2000). This finding has been observed in Huntington Disease as well (Cox and McKellin, 1999; Richards, 1996). Clearly, these kinds of notions (family resemblance/age at which cancer strikes) play an important role in attempting to make sense of family history and ascribing personal risk. They may serve as markers and be part of a cognitive attempt to understand, cope with and control what is happening. Undifferentiated fears are extremely difficult to live with.73 Life markers can be used to reduce a sense of randomness, and in the case of hereditary disease, both contribute to and reduce anxiety.

73 I thank Elvi Whittaker for drawing my attention to this point.
about it as well. When confronted with a number of disturbing events, we insist on finding a pattern.

Women used their experiential knowledge not only to construct notions of personal risk, but also to override physicians' advice when it seemed wrong. The medical recommendation most commonly rejected was that they were too young for mammography. Frequently participants were told that breast cancer was a disease of older women and they did not need this kind of surveillance. Despite their family histories, physicians did not always support their concerns or take action. Many of the younger participants said they had to complain and pressure their physicians to obtain these services. They looked to medical technology (in particular, mammography) as the best hope for early cancer detection and improving their chances of survival. Gillian talked about pushing her family physician to get annual mammography following her sister's diagnosis at age 37. Gillian was about 33 at the time.

It's not that they were offering, I was asking for them [mammograms]. And saying, you know, I want that, and well you're, you know, you're too young. Like, um, I think it was when I had a mammogram, um, (pause) um, after [my sister] got cancer, and I hadn't had a mammogram I don't think for a while, and I said, you know, I want to get a mammogram. And they said, uh 'cause at the time I don't they were doing it every year. You know it was just every, like two or three years or something. And I said I wanted to get one, and they said, well, no you, you know, you're not, you're not old enough and stuff and, and I said, I, you know, I just said, I, I want one and I want it within the week.

Marilyn, who was 29 years old at the time of our interview, also talked about the

74 The Canadian Cancer Society breast cancer screening guidelines currently recommend that women have mammograms every other year from age 50 to 69. Because of the controversy about its efficacy in younger and older age groups, women under 50 and over 69 are advised to check with their doctors. Screening recommendations for individuals from at-risk families, however, differ from that of the general population. Currently, the HCP recommends that a woman from a hereditary cancer family begins screening 10 years prior to the youngest age of cancer in their family. For example, if the youngest person in a family to have cancer was 35 at the time of diagnosis, other at-risk individuals would be recommended to start annual mammography at 25. Many family physicians are unaware of these guidelines.
difficulty of obtaining a mammogram.

It’s really hard. They even have this breast / it’s called the Breast Centre I think or Breast Clinic or whatever in [city]. That’s all they do is mammograms. And like everybody just loves them. Well, I’ve gone twice now and all it is a hassle, because number one they don’t want to give me a mammogram, and number two they treat me like I’m too young to be there anyways.

Leslie pressured her surgeon to remove a lump she found in her breast. She considered herself at high risk for breast cancer based on her experiential knowledge. Multiple family members, including her mother and sister, had been afflicted with cancer. Although the surgeon knew her family history and suspected that there might be a genetic mutation in the family, she was reluctant to do the lumpectomy. Leslie was told that in women of her age most breast lumps are benign. Yet, she relied on medical technology and expertise to deal with her own way of knowing.

Like my surgeon was / suspected that I was a gene carrier. And she still didn’t want to give me my lumpectomy. And she suspected that I was. Stupid. Well I had to tell them, you know, I’m twenty-seven years old, I’m not an idiot, you know. I have a big lump sitting in my chest and if you don’t cut it out, I will take a steak knife and take it out myself. I don’t care. It’s coming out. And that, I shouldn’t have to do that.

From the vantage point of power, the behavior and responses of these individuals can be read as a challenge to authoritative knowledge and medical networks of power. The conflict between experiential knowledge and professional knowledge frequently played out in access to medical resources for younger women. It is important to note, however, that not all participants experienced such confrontational interactions with their medical providers. Many felt fully supported by family physicians who took their concerns about family history seriously and supported their decision to have mammography.
Summary

Although epidemiological studies have identified family history as a major risk factor for breast/ovarian cancer, there has been little investigation of how family history influences women’s knowledge about their cancer risk. Quantitative surveys consistently show that women with family histories of breast cancer have high levels of psychological distress and anxiety, as well as persistent and intrusive thoughts about developing breast cancer (Baider, Ever-Hadani et al. 1999; Baider, Cooper et al. 2000; Hailey, Carter et al. 2000). Other research confirms that women with a family history of breast cancer see themselves as vulnerable to getting the disease (Beckett, Redman et al. 1991; Vernon, Voget et al. 1993; Chalmers and Thomson 1996; Chalmers, Thomson et al. 1996). Missing from current studies, however, is an examination of how knowledge is shaped by different ways of living with, experiencing or knowing breast cancer.

I draw on Abel and Browner’s (1998) characterization of experiential knowledge to describe how participants come to know breast cancer. In their paper, “Selective compliance with biomedical authority” they discuss two types of experiential knowledge: embodied knowledge and empathetic knowledge. They define embodied knowledge as knowledge derived from embodied experience (in their study, pregnancy) and empathetic from close contact or emotional ties with individuals engaged in a particular experience (i.e. caregiving). In this study, embodied knowledge refers to women’s actual experiences with breast cancer, with chemotherapy and radiation, and with surgery. It is knowledge gained by living with the disease, including ongoing physical and emotional changes. Empathetic knowledge, on the other hand, refers to knowledge that is acquired by living with or having close contact with others who have a particular illness. Keller (1985) described empathy as “a form of
knowledge of other persons that draws explicitly on the commonality of feelings and experiences in order to enrich one’s understanding of another in his or her own right” (p.117). In this study, family members acquired empathetic knowledge of cancer, its particular manifestations, the side-effects of treatment and the likelihood of survival, from personal experiences in living with or caring for relatives who have had the disease. I also expand this concept to include knowledge that is acquired about particular others (and with whom one shares a biological connection) that is obtained through less direct means. For example, some participants came to know cancer through family stories passed down from one generation to the next. Although far less personal, this form of empathetic knowledge is also pivotal in shaping meanings about hereditary cancer. It may give rise to distinctive vulnerabilities (personal constructions of risk) that come from being part of this group.

As Abel and Browner (1998) point out, although one type of knowledge derives from “direct sensory experience” (p. 315) and the other from emotional bonds between individuals, uniting these two types of knowledge is their particularity. Particularity brings to bear the strong role that subjectivity, social location, context and experience play in knowledge claims. For over two decades, feminist theorists in philosophy and other disciplines have stressed the significance of particularity of context and the ‘specificity of the knowing subject’ (Code 1993) in the development of knowledge. Further, feminist epistemologists have insisted that knowledge is obtained both individually and in community (Code 1991; Alcoff and Potter 1993; Code 1993). It has been argued that interpersonal experience is necessary for individuals to have beliefs and to know (Bleier 1984; Code 1991; Nelson 1993). This view purports that knowledge is not an objective activity based on rationality and self-interest but is a process that emerges and is constructed in dialogue with
others. It is relational and interactive (Alcoff and Potter 1993). Indeed, within this study we see that knowledge of cancer is obtained within the context of the individuals’ story as well as within the family’s broader story. Based on experience, family members construct and share their knowledge about a particular disease as well as knowledge that the disease is familial.

Although the characterization of experiential knowledge as embodied and empathetic serves a useful heuristic function, the distinction is not rigid. Empathetic knowledge may shape how embodied knowledge is interpreted, and embodied knowledge empathetic (i.e. my embodied experience of cancer may be influenced by how I saw the disease play out in my sister’s or mother’s life). Especially for families with hereditary disorders, the two are often intertwined as they contribute to experiential knowledge that extends across generations and evolves over time. Further, neither category is static. Each may be revised to reflect insights gained from new experiences. For example, although Marlee expected to get cancer at some point, she did not expect to develop it at such a young age. Based on her experience, her family legacy has been revised to include the knowledge that cancer can occur in women in their early thirties as well as late thirties. Less toxic and more successful treatments may also change the way cancer is experienced and known over time.

It is also important to stress that neither empathetic nor embodied knowledge is a homogeneous category. Families play a central role in shaping and contributing to knowledge about hereditary cancer and as can be seen from the participants’ accounts, this varies greatly. For some people in this study, empathetic knowledge means living with a person who has or had died from cancer (tangible knowing). It is affected by the kind and amount of shared experiences with relatives, the variability of a relative’s illness trajectory,
the extent of suffering witnessed and the sheer number of family members who have died from the disease. For others, knowledge of cancer is solely a matter of what has been shared through family stories and hearsay (distant knowing). There has been little or no contact with the people who have had the disease. Although these participants possess knowledge of their family legacy, it is far less personal. Further, one participant came to know her family legacy solely by accident (accidental knowing). Likewise, embodied knowledge can take different forms. In this study, participants had breast cancers ranging from stage 1 and stage II disease to recurrence and terminal illness. Clearly, disease severity would lead to different experiences and constructions of embodied knowledge and what others would see (empathetic knowledge). Further, although one might think of embodied knowledge as more valid (or real), I would argue that in the case of hereditary cancer (and I suspect other illnesses) empathetic knowledge can be just as poignant. The intensity of that knowledge derives from the fact it is grounded in relationships. As many participants articulated, the situation of having one’s sister, mother, grandmother suffer from breast/ovarian cancer is a traumatic one. Watching the pain, misery and suffering of others is emotional and extremely difficult. Living with a mother and two sisters who suffered from cancer and the effects of treatment, for example, gave Nancy the knowledge that she did not want to experience these things herself. Their experiences had a profound impact on how she viewed her personal risk and sense of future, which in turn influenced her decision to seek prophylactic surgery.

While this chapter has focused on the familial context of knowledge production, it is important to recognize that individuals’ experiential knowledge of cancer is also shaped by

75 I wish to emphasize the importance of biological connections here. I suspect, for example, the knowledge of cancer in a friend’s family is not likely to affect a person as much as knowledge of cancer in their own family even if learned through hearsay.
76 While this category represented the smallest number of participants, it may enlarge over time if testing becomes more available.
external knowledge. As feminist scholars and others remind us, individuals and family are socially and historically located (Meyers 1997). Knowledge about the disease develops within a broader community -- social, cultural and medical -- that views the illness in a certain way (Good 1994). Epistemological communities are multiple (Nelson 1993).

Although I have not examined this in depth, Marilyn’s comments pointed to the influence of social discourse and representations of cancer on her understandings of the disease. “I don’t know, I’ve always been scared of cancer for some reason, but not because of family or anything like that, it’s just always, I probably just thought it was horrible. Like something you would never want to have. It seems like it’s all over and terrible stories about it.”

Participants also drew upon medical information and professional knowledge in the construction of their knowledge claims. Indeed, medical information has the ability to set in motion new understandings or re-evaluation of experiential knowledge. Recall Catherine’s experience. Genetic information derived from genetic testing altered the way she viewed her family history of cancer as well as the way she viewed her own risk for the disease. To the extent that medical information is not just about facts, but has meanings attached to those facts, we can posit that it has transformed this woman’s experiential knowledge. Yet I think we should be wary of giving genetic information too much power. As will be explicated in the following chapters, for many women from hereditary cancer families genetic testing (more specifically, information gained from it) just confirmed something they already knew. Women used experiential knowledge as basis for deciding whether they were at increased risk even as biomedical information contributed to that knowledge. At the same time, experiential knowledge sometimes conflicted with medical knowledge. Because breast

77 Several participants spoke about the vast amount of attention devoted to breast cancer by the media. This included television news, talk shows, popular magazines, newspapers, as well as public health campaigns.
cancer is perceived to be a disease of older women, for example, many participants reported being denied access to mammography because of their age. But experiential knowledge is a powerful force. People experience themselves as knowers and interpreters of this lived experience. Most participants used this knowledge to accept or reject clinical recommendations and to gain access to services they felt they needed.

In summary, this chapter highlights the connections between personal and family history, relationships and knowledge claims, on the one hand, and constructions of risk identity and conceptions of self, on the other. It illustrates that experiential knowledge about breast cancer is derived from different ways of living with and knowing breast cancer. Most of these are connected to strong family histories of the disease, but some are not. Experiential knowledge encompasses two types of knowledge: embodied and empathetic knowledge. The first is sensory, while the latter is derived from relationships and connectedness to particular others. These knowledges are unique to each family context, but also reside in a shared domain that is shaped by social, cultural and medical factors. To this end, experiential knowledge begins to give us a sense of how people may view themselves ("the self") in terms of hereditary or familial risk. It also provides the groundwork for looking at choice related to genetic testing and how this intersects with moral agency and understandings of self. I begin to explore these issues in the next chapter.
CHAPTER SIX:

Making Choices

It wasn’t what was at the end of the road that frightened Amnu as much as the nature of the road itself. No milestones marked its progress. No trees grew along it. No dappled shadows shaded it. No mists rolled over it. No birds circled it. No twists, no turns or hairpin bends obscured even momentarily her clear view of the end. This filled Amnu with an awful dread, because she was not the kind of woman who wanted her future told. She dreaded it too much.

--- Arundhati Roy, *The God of Small Things*

I could have stopped there. I could have chosen ignorance but I did what you would have done – what you’ve already done if you’ve read this far. I chose knowledge instead. Most of us will. We’ll choose knowledge no matter what, we’ll maim ourselves in the process, we’ll stick our hands into the flames for it if necessary.

--- Margaret Atwood, *The Blind Assassin*

Introduction

As the preceding chapter illustrated, women come to genetic testing with diverse family histories, experiences and knowledge of breast/ovarian cancer. Some women are strongly aware of their family legacy of the disease. For others, cancer is a recent family event or they may have been affected by breast/ovarian cancer themselves. And for others still, the family history of the disease is something that has been learned by chance. The meanings that individuals ascribe to hereditary cancer are shaped by biographical, familial, medical as well as social factors. Similarly, concepts of hereditary risk are constructed within the context of lived experience. Participants’ stories point to the complex interweaving of experience and ongoing family dynamics in the construction of knowledge about breast/ovarian cancer and notions of subjective risk. They also provide the context for understanding what brings people to genetic testing. This route can occur in different ways.
In this chapter, I seek to understand why and how people come to genetic testing. I specifically explore the moral territory involved in their decision-making. How do participants understand genetic testing with respect to their own moral agency; namely, their sense of self and individual goals? What reasons do participants give for choosing or declining genetic testing in terms of the self and others? What is the nature of their responsibility? Analysis of the findings represents my interpretation of how choices around genetic testing involve three interrelated aspects of self: the embodied self, the relational self and the social self. I use these elements to refer to the manner in which participants viewed genetic testing when thinking about their physical selves (embodied self), their families’ health and well-being (relational self) and their general relationship to unknown others (social self). I do not mean to suggest that these three elements of self are mutually exclusive – clearly, they are inextricably intertwined as the construction of self at one level (e.g. social self) will have an effect on the construction of self at another (embodied or relational self). Nor do I suggest these three categories are fixed or exhaustive. Rather, I use these accounts of self to illustrate the complexity of choice and decisions involved in genetic

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78 My definition of the social self is a slightly different take on philosophical definitions of the social self. Rejecting highly individualistic approaches, feminist and communitarian theorists view social relations and connections with others as intrinsic to the shaping of self. The claim that the self is socially determined means that one’s aims and desires are determined largely by the family/community to which one belongs (Barclay, 2000). Feminist theorists also draw attention to how social and political structures affect individuals’ identities and ways of life (Sherwin, 1992; 1998). In discussing the social self, however, I am looking specifically at an individual’s expression of self in relation to unknown others or her concern for society at large. This, of course, will be shaped by the family, community and larger political and social structures.

79 I also agree with the position taken by many post-structural theorists that the unitary self is an illusion and that we are composed of multiple selves. Moreover, one self is dependent on another self and subject to change. As Walker (1998) writes: “A view of selves that fits with this ethics is one in which a self itself is understood in terms of a history of relationships among its various temporally distant and concurrent aspects. We are layers of various overlapping histories of traces of many encounters and relationships; these coexist in various states of stratification or alternation as we live our lives. My present self owes debts to my past one, and my future self is deeply dependent on the choices and self-understandings of my present one” (p. 119). Lorraine Code (1993) also maintains that any fixity claimed for the self will be “fixity in flux.” However, I also agree with her assertion that “something must be fixed to “contain” the flux even enough to permit references to and ongoing relationships with “this person” (p. 34). Knowing others occurs within the domains of this tension.
testing. I attempt to demonstrate how choice is not an abstract activity, but is related to a person's understanding of self and moral agency. This, in turn, is influenced by many intersecting factors including context, family history, experiential knowledge (empathetic and embodied) and relational commitments to others. 

The chapter is divided into three sections. In the first section, I explore the reasons participants cite for deciding to undergo testing as constructed through the above elements of self. In the second section, I examine the accounts given by participants who are eligible but decline testing using the same components. I conclude by drawing attention to how the self in relation to others (both known and unknown) is integral to decision-making about genetic testing.

In order to situate how individuals come to genetic counselling, I'd like to first summarize some of the key aspects of participants' medical and family history. As indicated in Table 5, 39 of the 53 participants underwent testing. Of these, 14 had been affected by breast or ovarian cancer and 25 were cancer-free but considered at high-risk based on family history. Three participants from the same family (one with breast cancer, two without) had sought testing but were waiting for the index test results before proceeding further. Six participants refused testing even though they met eligibility criteria. In addition, I interviewed four individuals (2 women, 2 men) who were spouses and one son of participants who underwent testing. It is important to recall that with the exception of those who are

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80 It is important to note that I do not include in this chapter a detailed examination of how public discourses about breast cancer and genetic testing (newspapers, journals, television, the internet) influence women's and men's decision-making around testing. My purpose here is not to analyze the data so much from the aspect of social discourse (although an important consideration) but from philosophical concerns with the nature of self and moral agency. I wish to examine how people understand genetic testing in their particular lives before trying to assess the social influences upon them. At the same time, I recognize that self and agency are developed within social and political structures, and influenced by social discourse, which will impact these constructions in particular ways. I do explore some of the ideological discourses about breast cancer and genetic testing in Chapter 8.
Table 5

Genetic testing for BRCA 1/2 mutations: Participant profile

<table>
<thead>
<tr>
<th>Participant profile</th>
<th>Female</th>
<th>Male</th>
</tr>
</thead>
<tbody>
<tr>
<td>Received genetic testing: Affected by cancer</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td>Received genetic testing: Unaffected by cancer</td>
<td>20</td>
<td>5</td>
</tr>
<tr>
<td>Declined testing</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Awaiting test results before proceeding further(^a)</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Family members, not eligible for testing(^b)</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>45</td>
<td>8</td>
</tr>
</tbody>
</table>

\(^a\) Of this category, one woman was affected by cancer and two were not.

\(^b\) Participants this group are spouses or partners of those who were tested, and thus not eligible for testing. I also included one son in this group. He was from the family awaiting test results and vague about whether in the future he might consider testing for himself.
afflicted with breast/ovarian cancer below the age of 35, or those who are of Ashkenazi Jewish descent, the BCCA Hereditary Cancer Program restricts testing to individuals with a combination of personal and family history of breast/ovarian cancer. In this study, none of the participants was offered genetic testing on the basis of a personal cancer diagnosis alone.

**Embodied self**

As previously stated, empathetic and embodied knowledge contribute to the construction of an individual’s risk identity. Similarly, construction of a risk identity has profound implications for the way women think about their bodies and consequently their sense of present and future self. In my usage of embodied self, I focus on those aspects described by Browner and Press (1996) and Gordon (1990) to include constructions of self based on a woman’s experiences of her body and its physical nature. The embodied self takes into account how embodiment affects how we see ourselves, how we live and the decisions we make. As Dodds (2000) writes: “Different kinds of choices are affected by the degree or extent to which bodily processes are involved and by the personal or social significance attributed to such processes” (pp: 219-220). I also concur with Church (1997) that selves are not separable or identical to bodies but “are created and sustained by the establishment of particular sorts of interconnections” (p. 8). The body does not make the self, but the body (well, ill, able, disabled, etc.) influences understandings of self. Thus, illness may set limits on the self through the body. To recognize this is not to dismiss the importance of culture and social location in shaping concepts of self, but to understand embodiment as a source of knowledge and authenticity (Howson 1998). Elliott (1999) makes a similar point with respect to the link between biology and a social/cultural identity: “There may be no biology independent of culture, but neither is there culture independent of biology. How a given
society conceives of its members, how they conceive of themselves, is connected to certain biological facts” (p.48).

For most study participants, breast/ovarian cancer posed a real physical threat to their health, their bodies and sense of future self. Based on lived experience, many equated breast or ovarian cancer with death. The notion that death from breast cancer is inevitable may reflect, in part, the historical reality of the disease before more successful treatments became available81 (Rosenbaum and Roos 2000). (The survival rate from ovarian cancer, on the other hand, remains very low even today). But it also reflects the concrete reality that most participants had faced. In recent years, medical and activist discourse has shifted to emphasize that breast cancer is not fatal (Lerner 2000). Commonly heard is the message: if breast cancer is detected early enough, women can survive the disease (Zones 2000). Yet for many participants this message just did not hold true. Lorraine, who is a public health nurse and was diagnosed with breast cancer at age 47, explained it this way.

The survival rate [from breast cancer] is really good and they [physicians] are quite confident if they find it early people survive. It's just in our family that was never our experience. Everybody who got it died quite quickly actually... Aunty M. and Aunty E. it seemed like within a year or two after diagnosis they had both died. So my experience, my family experience isn't that you do well and you survive.

It is important to add that Lorraine did not reject the medical paradigm. Rather, she sought medical treatment that she considered would best meet her needs. She was very aware of her family’s cancer legacy (both breast and ovarian cancer) and the risk it imposed on her. She used experiential knowledge as basis for deciding to pursue prophylactic surgery even as

81 With new and hopefully better treatments, we may begin to see intergenerational differences in the way or how soon a family member affected with cancer died.
biomedical information shaped that knowledge.

I just knew that I had to do this. I don’t know why I knew, but I knew I had to do it and I had to get going on it and not keep waiting and waiting.

She went for genetic counselling prior to the surgery, but testing was not yet available.

They [genetic counsellors] kept saying the genetic testing was coming very soon and I should wait to have that test, but I thought to myself no, I’m not going to wait. Dr. ___ said based on that family tree too she was pretty sure we had a genetic defect, so I just decided that I was going to do it anyway.

It was during the ‘prophylactic surgery’ (a bilateral mastectomy) that a 1.8 cm tumor and little specks of cancer were found throughout Lorraine’s right breast. The cancer had been previously missed on both clinical exam and mammography. Lorraine later underwent genetic testing when it became available. She said it confirmed what she already knew. “I mean I knew being a nurse there’s something wrong with the family. Like why is everybody dying of cancer?” She indeed had a BRCA1 mutation.

Including Lorraine, all of the 17 women\(^{82}\) afflicted with breast/ovarian cancer viewed cancer as a persistent threat. As other studies have shown, uncertainty about the future and fears of recurrence were ever-present and motivated them to seek testing (Lerman 1996; Tessaro, Borstelmann et al. 1997; Rosenbaum and Roos 2000). They sought genetic information about hereditary risk, in part, to guide further medical management. They perceived genetic testing as providing information that would enable them to protect themselves. Haunted by images of the past, these women said they would do anything they could to prevent cancer from re-occurring. With the exception of one woman who was in the terminal phase of her disease, information about BRCA1/2 mutation status was instrumental

\(^{82}\) This number also includes two people with breast cancer who decided not to seek testing, and one who was awaiting test results.
in helping affected participants decide whether to pursue prophylactic surgery or not. Sandra, who was diagnosed with breast cancer at age 37, put it this way:

You know having gone through that [breast cancer] it was easy to make the decision that I didn't want to do it again and take that chance. And I think seeing that my mom had it twice and that my aunt had it twice, only reassured me that I was making the right decision to get tested and then making the decision to have the surgery. Then after I had the test done and after I had surgery, my mom found out that she had ovarian cancer and breast cancer for the third time. And my aunt, actually right after I had been tested I found out, I met my aunt, she came down here from Ontario, and she was quite sick from cancer that had grown. She had her ovaries removed, but the cancer was growing where her ovaries were, and she ended up passing away just this last fall. So I think I made the right decision.

Most affected women viewed information gained from genetic testing as allowing them to make choices about medical management that might improve their survival. In that sense, genetic testing was viewed as empowering. Martha wanted to be tested and learn her genetic risk status, because as she put it, "knowing gives you more control." The ability to know her genetic risk status offered her some control over an uncertain disease. Marlee, who was diagnosed with breast cancer at age 33, also talked about genetic testing in terms of knowledge, awareness and prevention.

My mom’s doctor spoke to her quite a bit about it [genetic testing] after finding out about me. So yeah, it just went from there, but no it was/ it interested me right away. It interested my mom right away... To me the more I can know the more I can help myself...right?

It's 'cause when you go through this [breast cancer] you're more aware and keep even closer eyes [on it], more of a preventative thing.

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83 In my study population, only two of 17 women who had breast cancer elected not to undergo testing. Their reasons will be explored in the next section.
84 Interestingly, although Marlee's mother struggled with several bouts of different cancers (breast, ovarian, lymphatic), only when Marlee developed breast cancer did her physician begin to think about the genetic/hereditary etiology of the disease. Usually, it is the past that situates our understanding of the present, but here it is the present that gave new meaning to the past. Commercialization of genetic testing is likely to result in testing criteria being more lax. Thus, we may see more families exemplifying this pattern. Genetic information may lead to alternate visions of health and family
Lucie, who had breast cancer in her mid-thirties, also expressed the view that genetic information would aid in medical decision-making. She did not perceive this test as anything extraordinary; nor was she surprised by her results. Rather, the test just confirmed medically something she knew through subjective experience.

Some of those who did not have breast/ovarian cancer, but were at high risk based on family history, expressed similar sentiments. Brenda’s decision to be tested was also influenced by her family history, which included several aunts, cousins as well as her mother dying from breast cancer. At the time of our interview, her older sister (then aged 48) was struggling with ovarian cancer after having had breast cancer when she was 30 years old. A BRCA1 mutation had already been found in several members of her family, including Brenda’s sister with cancer. Several times during our interview, Brenda talked about genetic testing providing her with specific information about her body and the opportunity for choice. In her words:

Life is too short to be worrying about whether you have breasts or not, and I certainly want to live it to the fullest. And I think I figured one of the reasons why I wanted to find out if I had the gene was because if I did have it, I wanted to deal with it and have it [prophylactic surgery] done with while I was still really healthy, and had a good mental attitude. I didn’t want to be sixty doing this.

At least we know. This wasn't something that we could find out and do at all before. And I think the more people that find out that they can do this, um, the more informed decisions that they can make, you know? We need to know as much as we can about our bodies.

Brenda was found to be a BRCA1 mutation carrier. She saw genetic testing as providing information that allowed her to make an informed decision. While she did not have cancer, she had a prophylactic double mastectomy and oophorectomy in the hope this would reduce her future risk of getting the disease. She recognized that these surgeries came with their own costs, but viewed the latter as preferable to the cost of cancer.
It's one thing to lose your breasts and get an implant or whatever, it's another to lose your breasts and your hair, and your eyelashes and feel sick, and, you know, wonder if you're getting the cancer, you know? This is a lot easier than that. So, it makes you feel kind of lucky then, you know. You're getting the easy end of it. I feel sorry for the families who can't find out if they have the gene.

Susan also drew on empathetic knowledge of others’ experiences in making her decision to seek genetic testing. As a young child (12 years old), she had watched her mother struggle with breast cancer and the debilitating effects of treatment. Later, her grandmother died from ovarian cancer and not long after that, an aunt (her mother’s sister) developed breast cancer as well. Her family history gave Susan the knowledge that she did not want to experience this disease herself. Concern about personal risk provided her with a strong inducement to pursue genetic counselling. Indeed, she was the first in the family to explore the genetic implications of the disease. She was 29 years old at the time.

I went by myself for the initial appointment and [the genetic counsellor] talked to me, she told me a little bit of what it was about and I had spoken to my mom about it as well. Later on we went as a group. I think my aunts came out and my mom came out, so we all went in together and I kind of just sat back and listened... My mom got tested first and she came back that that she did have that gene and my aunt as well. That's when I think I started getting scared that I would probably have it as well. I always wanted to get the testing up until the point it where it was my turn to get the results. It did go through my head because [the genetic counsellor] had mentioned some people change their mind and they just say well I don't want them. That did run through my head just briefly because I like to know things whether it's / because I felt that I could prevent or do some of the preventative surgery that people get done that my mom had done and my aunt had done. That's why I wanted to know early.

Although she opted for testing and receipt of her test results, Susan’s account helps illustrate for some people this can be a difficult decision. There were times when she wavered about whether she indeed wanted to know her genetic status or not. She perceived a positive result as condemning her to a certain fate. Ultimately, however, the hope of
preventative’ action took precedence. Jan, who came from a family in which a mutation had been previously identified, also expressed some initial ambivalence about knowing.

I thought about it a long time. Do I really want to know? What difference would it make? And I finally decided it was a good thing to do because I already thought, I don't know if I even knew there was a gene, I just knew it was strong in the family. And I thought I am probably going to get this, so it can't be any worse to know that I am carrying the gene and it could possibly better.

Knowledge is power

Jan’s comments fit into a larger discourse shared by many participants: that knowledge is good and knowing cannot be worse than not knowing. Not only is genetic information relevant to informed decision-making, but it allows one to understand, cope with and possibly take control of what is happening. As Martha stated: “I needed whatever information I was going to receive, and I was...grateful is the wrong word, but it’s, I think that the value of having this testing for women cannot be underestimated.” The husband of a participant with breast cancer also talked about the value of knowing.

Husband: [My wife] and I were talking about coming back after we had been in [to genetic counselling]. Do you really want to know? Do our grandchildren really want to know? It may discourage them from marrying and having kids. There are a whole lot of implications. And we said yeah, we still want to know because the important thing is what you don’t know can hurt you.

L: What you don’t know can hurt you?

Husband: Can hurt you. What you do know can’t hurt you. If you know it and you do it, then you knew you were going to do it. If you know the risks, then you can’t say you didn’t know. But to not tell someone, then let them run the risk and find out the hard way, I don’t think so. So we said no, this is good stuff. If we are going to get this cancer thing ever beat.

Decision-making is typically understood as a process that involves reflection about the implications and outcomes of a specific action or event. Yet, a few participants spoke of being just “too curious” not to be tested. In each of these instances, a mutation had already
been found in their family. Their decision to seek testing did not reflect contemplative choice as it is typically constructed — that is, the weighing of alternatives and balancing of perspectives — but was more of a gut reaction. They said as soon as they learned about the familial mutation they just had to know whether they carried it or not. Little consideration was given to considering the implications of this information. As Marilyn, age 28, put it:

As soon as I found out about the gene, all I wanted to do was get tested. Because I just had to know. I don’t know [whether it’s] because I am stubborn and nosy, but I had to know.

Carolyn also spoke about testing in this way. Like most participants, she had experienced the immediacy of cancer. Indeed, one of her earliest memories is seeing her aunt’s scarred chest after a mastectomy. Strongly aware of her own risk, Carolyn (now age 21) had been doing self-breast exams since the age of 15.

Once I understood everything that was going on and that there was this gene and everything, I wanted to know right away. So, not so much that it changed my life or anything, but just so I know what’s going on with my body.

Other participants who were unaffected but at high risk cited relief from uncertainty as a reason to undergo testing. These findings are consistent with both qualitative and quantitative studies that suggest that knowing one’s genetic status (either positive or negative) reduces the stress of uncertainty for some women (Lerman 1996; Bernhardt, Geller et al. 1997; Lerman 1997; Tessaro, Borstelmann et al. 1997). Like those with cancer, many of these women thought that a positive result would be useful in making decisions about medical surveillance or prophylactic surgery. Likewise, a negative result would alleviate fear about the future. As Kate said: “I sort of wanted to know for a backward reason. If you are negative, you don’t have to worry about it anymore.” Alice expressed similar sentiments.

I preferred to know because if I didn't carry the gene then that would be less stressful. Do you know what I am saying? Like why worry about it? If you don't carry it and
then you can find out, you know one way or the other and Oh then also I wanted to know if I did have it because then you know then I could get into this High Risk Program and sort of be more aware of it, of my chances and my risks because they increased greatly.

The above accounts suggest that women who decided to undergo testing were, for the most part, unequivocal in their decision-making. Embedded in their discourse is the neo-liberalist view about information and choice; that knowledge is power and it is better to know than to not know. They shared the view that information about their mutation status would make them more aware and in turn, enable them to take action in defense of their bodies. In terms of the embodied self, most saw themselves at serious risk for developing cancer. They knew about the unpredictability of cancer, the trauma it causes and valued their lives. While a few participants embarked on testing without giving it much thought, most used it for pragmatic ends. Genetic information aided in the selection of specific strategies for disease prevention. Seen from this perspective, genetic testing is not just another form of medicalization as some have suggested (Lippman 1998; Finkler 2000; Press, Fishman et al. 2000). It offered these women the best hope for control and perhaps improved survival. Women may have embraced the medical model, but they used it for their own ends. They used genetic testing to challenge and perhaps transform the embodied experience. That is not to say participants were universally happy with their options (mastectomy, oophorectomy, or aggressive screening), but they saw it as what they had to do in order to beat the disease.

Thus far, I have described attitudes toward genetic testing that were primarily unequivocal in nature. While they constituted a very small group, a few participants (n=4) initially declined testing but later changed their minds. In each of the cases, cancer as a life-

85 Much has been written about medicalization, but here I refer it to mean the control of women's bodies and women's health through medical practice and medical procedures (Morgan, 1998; Ferguson, 2000). At the core of medicalization is the view that certain life experiences, processes or conditions become the domain of medical attention and thus subject to medical control (Zola, 1978).
threatening disease took on added significance. Anna, for example, received genetic
counselling but decided not to be tested initially. She was diagnosed with breast cancer at age
47, but felt that her treatment and follow-up care were good. The breast cancer diagnosis of a
friend, however, impelled her to revisit her decision:

I talked to the people in genetic counseling at the clinic and I said basically: "Well, what would I do even if I did have it [BRCA1/2 mutation]?" They said: "Well, the only option would be prophylactic mastectomy, which we don't recommend, but you know." So I said: "No, I don't want to know. I'm not interested. I would never do that, so what is the point of knowing and having the shadow..."

Then, my other best friend at school got breast cancer. She had had a mammogram in June and in January she found a lump -- this is a woman who is surrounded by people with breast cancer -- she decided to ignore the lump because she had a mammogram in June and it was fine. So she ignored it from January till June, so a year from her last mammogram and she had 5 lymph nodes involved...I was just absolutely freaked that in one year you could get 5 lymph nodes. I was thinking, they test me, that was the option, we can test you every 6 months -- ultrasound, tumor markers I have anyway, mammogram...But when this happened to [friend] I started thinking, OH MY GOD, 5 LYMPH NODES. LIKE IT COULD GROW THAT FAST? I just didn't know that. So I went and just sort of threw it out at the end of my last checkup ... I am going to go for the genetic testing and she [the oncologist] looked really surprised and said "great, good, good choice, okay" and set it up.

Reda also talked about a change of perspective. She first learned about genetic testing
when she was 22. Her mother, who had breast cancer when Reda was an adolescent, and
several of her aunts had already been found to be mutation carriers. Initially, she did not want
to have anything to do with testing. She described it as “almost God-like to get tested” for the
disease. In a second interview a year later, she felt quite differently. She attributed her change
in perspective to learning more about the seriousness of cancer and just getting older. She
said that she would likely be tested in the next few years.

L: Last year when we talked, you weren’t really interested in genetic testing at all. Do you still feel the same?

Reda: No. Well, no, I don’t. I feel a little bit different about it now. Actually in my Biology 110 course I did a paper on genetic testing for breast cancer. I think it’s a little bit more scary now than before.
L: And why is that?

Reda: Because you're, you can foresee it coming.

L: It's a little bit closer to you, is it?

Reda: Yeah, yeah, a little bit closer. A little bit more severe. You know, I went from not caring to, to caring.

L: And did anything in particular bring that on?

Reda: No, I don't think so. Maybe my age. I see the seriousness of it, maybe.

These latter accounts demonstrate that individuals’ responses to genetic testing are not fixed or absolute. Just like one’s values and sense of identity, they may shift over time. However, this shift can only go in one direction: from not knowing to knowing. Once genetic information about mutation status has been obtained, the person can never go back to the state of being uninformed. Sachs (1999) calls this the “knowledge of no return.”

Relational self

Locating the self in the empirical realm, feminist theorists have called attention to the importance of interpersonal relationships and context in shaping agency, autonomy and notions of self (Friedman 1997; Meyers 1997; Tong 1997). As previously discussed in Chapter 3, this conceptualization is denoted using the term relational self. The latter does not represent a single notion, but is more of a thematic term that encompasses a range of related perspectives. Underlying these various perspectives, however, is the premise that persons are socially embedded and relationships, connectedness with others and the community to which they belong are critical to self-identity (Sherwin 1992; Tong 1997; Barclay 2000; Mackenzie and Stoljar 2000).

Feminist theorists are not alone in this regard. Some mainstream philosophers such as Benn (1976), Dworkin (1988) and Feinberg (1989) have also written about the link between socialization and the self in the realization of autonomy.
Indeed, although genetic information provided the foundation for gauging individual risk and guiding medical decisions, responsibility to others proved equally important in participants' decision-making. This figured strongly in the reasons participants cited for seeking genetic testing. Most participants did not discuss choices to seek testing solely as individuated or autonomous agents, but also in relation to others. The relational self was made evident through moral commitments to others, a "kind of responsibility ethics" (Walker, 1998:105). In describing this ethic, Walker writes: "It aims to accommodate the richness and diversity of what people have reasons to care about and take responsibility for."

In fact, very few participants considered undergoing genetic testing just for themselves. Some participants thought they owed it to their families to have all possible health-related information in order to plan for the future. Responsibility to children, in particular, guided their thoughts. Michelle, a mother of a three-year old child, said that she assumes she will get breast cancer eventually. Her great-grandmother, grandmother and two aunts died from breast or ovarian cancer. When I spoke with Michelle, her mother was dying from cancer. Interestingly, she did not describe genetic testing as important to her sense of self or well-being. Rather, she saw it as providing one more bit of information that would help her plan for the future care of her children.

We [my husband and myself] live life as if we expect to deal with it at one point. ...[So] when Mom asked that would we do the genetic testing, and I said well yeah, especially if it would help my children. You know now that you have children, you see the bigger picture where we aren't in it...

If it comes back positive...because I have the children, I think I would actively start debating about whether to go on the tamoxifen or having them [breasts] chopped off. If we are found [to carry the genetic mutation], I think I would try and decide between one or the other because I have a vested interest in the future, in staying alive for them because they are young.
Lauren, who had breast cancer at age 42, expressed similar sentiments. She underwent prophylactic mastectomy and oophorectomy after learning she was a carrier for the BRCA1 mutation. She spoke of her decision to seek testing and undergo preventative surgery in terms of her three children. As a single parent and the sole provider, she saw herself as having a responsibility to manage her risks and stay healthy for her children. “Because their father has basically written the kids off, I have to be strong. I have to be healthy.”

Drawing on Sara Ruddick’s writings, Nina Hallowell (1999) argues that maintaining one’s health is linked to the ability to engage in ‘mothering work,’ i.e. nurturing children physically, emotionally and intellectually. She suggests that for some women, the decision to seek testing is guided by others’ needs. Indeed, findings from this study support this observation. When contemplating testing, women with young children frequently described their decisions as influenced by obligations to their children. Participants were concerned with staying healthy and being able to care for particular others for whom they felt responsible. In other words, relations and obligations to others were much more significant than “the individual self in isolation,” (Held, 1993: 59). These women feared dying from cancer and leaving their children alone.

Benefiting the larger family

Responsibility to family was also articulated in other ways. Many participants described their decision to seek testing as influenced by the desire to obtain information not only for themselves, but for their daughters and extended family. Because genetic risk is shared by all members of a biological descent, genetic information was generally perceived as a benefit to all kin. Participants often wanted testing so that they could provide children or
other family members with information relevant to their risk status. Mothers who had been 
afflicted with breast or ovarian cancer, in particular, wanted to spare their children a similar 
fate. The words of this participant, for example, illustrate how she viewed genetic knowledge 
as personally valuable, but getting information for other family members provided an even 
stronger impetus to undergo testing.

Ever since I've had cancer, I have been very interested in anything that’s come new 
or any you know progress they have made. I think in the back of my mind I kept 
thinking about my children. You know if they should have it and what is there for 
them you know. So and/when we found out my daughter had breast cancer that was a 
big shock. But you know you have it I think in the back of your mind, maybe this will 
happen you know but hopefully it didn’t, but in her case it did. Now hopefully she 
doesn’t have to go through any more you know in her young life and she’s taken 
some of the precautions [prophylactic surgery]...Because I wouldn’t want them to go 
through what I went through, no and there’s so much more now that they know which 
they didn’t when I first started. So, you know and I think it’s great that’s one reason I 
wanted to be in the [genetic testing] program so for their benefit and anybody you 
know else that I can help.

Kim expressed similar sentiments.

I wanted to get tested more for my kids. And for Alice, she’s the youngest [sister in 
the family]. She’s like my best friend, Alice and I. So yes, I kind of wanted to find out 
not more so for myself, but just to see if they would possibly have the gene or that I 
have passed it onto my children.

Martha’s comments also illustrate the link between testing and responsibility to 
others.

I felt that it [genetic testing] would also be important for me, but this was a secondary 
thing...the primary thing I was thinking about is risk for my family.

The few women I met who were dying from cancer viewed their participation in 
genetic testing as almost a duty. Obviously, at this stage information about genetic status 
provided no clinical utility for them. But these women framed their discussions of genetic 
testing in terms of its greater value to their daughters, granddaughters and future family.
They thought that genetic information would empower their daughters by placing them in a
better position to screen and manage their health. Ellen was quite emphatic about this point.

When I talked to Ellen at her home, she had been fighting breast cancer for two years, but had been recently assigned to palliative care.

I was, as a mother, thinking it was important for me to know, important for my children to know and understand and to have a preparedness for it.

I felt that there was far too much cancer in the family, that if they were doing this stuff [the genetic testing] it should be done. Not that it would help cure anything, but that they would have an awareness. It is better than walking in and always keeping your head in the sand. If you don't know anything, ask.

Ellen, like others, ascribed to the view that knowledge is power. She proceeded with testing on the basis if she was found to have a mutation, her daughters could be tested and be more aware of their potential risks. Moreover, while her own future was bleak, she hoped that involvement in the Hereditary Cancer Program would put her daughters in good stead to be contacted by the Agency about new developments in cancer prevention.

For Nancy, getting genetic information for her children was the only reason for obtaining her test results. Because of her strong family history of cancer, Nancy did not perceive the disease as a neutral probability. Rather, it had been a salient and ever present threat in her life. She underwent testing, but due to her fear of getting cancer, had both a prophylactic mastectomy and oophorectomy prior to getting her results. Although the information no longer had direct utility for her, she decided later to pursue her test results for the sake of her children. She learned that she did not carry a mutation. Despite having misgivings about her surgery, and wishing her test results had been made available much sooner, she viewed the test information as highly beneficial for her children.

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87 Despite having identified a mutation in the family, it took over a year for Nancy's test results to be made available to her. This occurred during the early stage of the testing program when people's blood was sent to Toronto for testing. A lab had not yet been set up in Vancouver.
Thinking back to the fear I had before that surgery, I'm very happy that it's negative. I am happy for the kids... For me to be negative is great for [daughter] and great for [son] because he won't pass it on.

Barbara also underwent testing solely for the benefit of her children. Two of her sisters had developed breast cancer and one had died from the disease. Because of her family history, Barbara underwent prophylactic mastectomy before genetic testing was available. Later, a BRCA1 mutation was identified in other family members. She then decided to learn if she carried the mutation for the sake of her children. She too proved to be negative.

I have children, so, you know to me it would just naturally follow that you would do that [have testing], so you would be armed with the knowledge for your children. And for me, knowing that I don't have the gene is wonderful, 'cause now I don't have to worry about my children...If I had tested positive then I would have had my ovaries removed as well. I mean that would be the, you know, the carry on with that. But for me I needed to know simply because of my children. I mean, now they don't need to be tested.

With no history of male breast cancer, all three men in the study underwent testing out of responsibility to their daughters and grand-daughters. David's response is typical in this regard:

I had my daughter and my granddaughters that could be affected if I have the gene. It doesn't necessarily mean that they would also have the gene, but then they could make some intelligent choices on them/ on their own if I were to be tested. And if I had the gene, I could tell them, say, okay, you know, it's up to you. You can just make your own decisions now. I have the gene and that there's a possibility that I may have passed it on to you, now you can at least make some, some choices. And it was on that basis that I was tested.

Hallowell (1999) cautioned that one of the outcomes of predictive testing is that individuals may begin to feel a sense of 'genetic responsibility ' towards others. Because genetic testing provides information about risks to the family, she speculated that feelings of genetic responsibility could limit choices, particularly an individual’s right not to know about their own genetic risks. In this study, most participants valued having this information both
for themselves as well as others members of the family. A few, however, felt constrained by knowing that a mutation had been identified in the family. While the choice between knowing and not knowing may be thought to be that of individuals, “autonomy is reduced when family members take initiatives to have genetic tests that involve family traits” (Dickens and Taylor 1996:114).

Bill, whose mother and other relatives died from breast or ovarian cancer, said that he had no choice but to participate in testing. As a male, genetic testing for the BRCA1 mutation had little impact on his health management. His decision to undergo testing stemmed from a sense of duty to provide his daughters with this information. He felt they should know whether they could inherit the gene mutation from him.

Having daughters, I didn’t even hesitate a bit to do it. I figured for me to find out, it had to be so... When [my cousin] phoned and said about this study, I didn’t have to think about it...I said I’ve got no choice having daughters. That’s the way I looked at it.

Bill, like many other parents, acknowledged he felt ‘guilty‘ for putting his children at risk. He believed he had a responsibility to be tested, so that his daughters could then determine and manage their own risks. In this sense, genetic testing compromised his right to “not know;” he said that he had no choice but to be tested. Yet, at the same time his decision to undergo testing seemed to be crucial to his moral identity. As Walker (1998) writes: “In making each other accountable to certain people for certain states of affairs, we define the scope and limits of our agency, affirm who in particular we are, show what we care about” (p. 16). Genetic testing, although limiting his choice to ‘not know,’ allowed Bill to reaffirm his commitment to his daughters.

While we usually think of parents being tested for children, some children were tested solely for the benefit of their parents. Chris, age 23, had no personal interest in pursuing the
test. She did not worry about breast cancer; nor did she perceive it as a significant threat in her life. (With the exception of knowing one aunt with breast cancer, her knowledge of the disease had come through the stories that her mother had told about other family members). Her mother (a mutation carrier), however, was very concerned about her daughter's health and urged her to be tested. Chris said that she underwent testing solely for her mother's sake.

L: I'm just sort of trying to get at a little bit about your reasoning to go for the test.

Chris: Well, 'cause my mom made me.

L: Oh, your mom made you?

Chris: Pretty much. Well she didn't make me, but it makes her, I mean it'll feel safer for us to go and her to know, sort of thing. So, that's why I went -- mostly for her and my sister.

Chris's reasons for testing were grounded in concern for her mother, rather than her own values and self-interest. Yet, while we need to pay attention to self-sacrifice, Bob and Chris's accounts indicate that the taking on of responsibility may not be a matter of coercion but is intertwined with notions of self. The responsibilities we assume intersect with who we think we are or want to be. This further supports the view that relationships serve as a "matrix for development of self" (Donchin 2000). Persons are not discrete, self-contained units but are selves that are bound up with others. What people seek from testing is moderated by social and familial relationships (including responsibility to others) that shape self-understanding and self-identity.

Responsibility and coercion

Feelings of genetic responsibility can play out in another way, however. As just shown, some participants felt so responsible for carrying a genetic mutation that they pressured other family members to get tested. Likewise, a few participants felt coerced to
undergo testing by mothers who thought this information was necessary for managing their daughter's health. For example, Jordan said that genetic testing led to a fracture in her relationship with her mother. Her mother, who had cancer several times, found to be a BRCA1 mutation carrier. Her mother felt the mutation explained why she got cancer and thought the information would enable Jordan to take appropriate precautions. Despite the pressure, Jordan refused to be tested and her mother took this decision as an affront to her. They argued about it and at the time of our interview, had not spoken to each other for a year.

Kelly also spoke about the pressure to be tested. Not interested in the information herself, she said she had little choice but to learn about genetic testing.

I didn't pay much attention to it [genetic testing] until my mom and everybody pursued it further. Then I didn't have much choice whether I wanted to pay attention to it or not...With my mom, there's not one visit that goes by, that she doesn't say something about it. Like we cannot go and have a visit without that being some type of focal line. She's really pushing me to be genetically tested.

Contrary to the notion that genetic testing provides choice, Kelly felt just the opposite. Her mother and aunts had obtained certain medical information that impacted her life. This posed new problems for her. She felt forced to live with information she would rather not have and from which she could not escape. Moreover, she wished her relatives had explored other avenues of awareness and breast cancer prevention besides genetic testing. In her words:

Kelly: Nobody explored what we could do for ourselves with out family history without this genetic stuff and that makes me angry. I think that they should have explored the whole realm before they decided what they were going to do because they made a decision for all us.

L: They did, didn't they?

Kelly: THEY DID and some of us don't want to live with that decision, but now we have to and all I could do is make the best of it.
At another point in the interview, she said:

I think it was no big deal to them [mother and aunts], but they didn’t think about what it was going to do to their kids and their grand kids. Because this is a never-ending thing now. Like we opened a box that’s never going to close, like it’s an open door to forever. Like I said once you open that door you can’t ignore what’s behind it.

Kelly’s comments are instructive in that they remind us facts (i.e. information that a genetic mutation exists in one’s family) are not received neutrally. People interpret them differently according to their own understandings, life context and experiences. Moreover, genetic testing differs from other medical tests in that one person’s decision to seek genetic testing will affect the choice of others. As Kelly states, genetic information has implications not just for her mother and herself but also for future generations to come. Whether Kelly decides to have genetic testing or not, her choice is affected by the knowledge that she is at 50% risk of carrying a mutation associated with breast and ovarian cancer.

People’s decisions to undergo testing can affect family members’ choice to know in other ways still. For example, Veronica (who did not have cancer) asked her mother to undergo genetic testing because of their extensive family history of the disease. Multiple members had died from breast and/or ovarian cancer. Yet, Veronica’s mother, who also had been affected by breast cancer twice, refused to be tested. Veronica was disappointed in her mother’s decision but proceeded anyway. She could be tested without her mother’s participation because a specific mutation had already been identified in other close relatives. In doing so, however, Veronica obtained information not just about her own genetic status but her mother’s as well. Testing revealed that she carried the same mutation as her mother’s sisters, meaning that her mother had it and passed it onto to her.

She’s dead now so, and she was only ... 67 when she died [from breast cancer]. So she’s, she wasn’t that old but she had chosen not to have the genetic testing done. I had encouraged her to do that but she wouldn’t. And um, even when she found out
that I'd had it done and I did have the BRCA 1 gene, she still would/she was still in
denial and felt that it didn't matter, didn't mean that she had it.

This example shows how genetic testing can lead to the disclosure of one's own risk status
by another. It may also lead to coercion and an impingement on choice for some. Yet, I
would be hesitant to say that genetic testing *per se* creates these kinds of situations. Rather, I
suspect that genetic testing fits into an ongoing narrative that is already shaped by family
dynamics and configurations of authority. The meanings people construct and what they do
with genetic information rests on particular assumptions about family roles and relationships,
which precede them. Yet, it could be argued, that genetic testing has the potential to
exacerbate a sense of responsibility or obligation between family members. In an attempt to
do good, family members who have experienced the trauma of breast/ovarian cancer may
pressure others to be tested whether they want this information or not. Likewise, some family
members may feel that their choice to know or not know is denied by the actions of others.
Clearly, as Veronica's situation shows, people may be told information about their genetic
risk that they do not want to know.

We need to guard against coercion, but at the same time it is important to recognize
there may be situations where people may not obtain information that could be beneficial to
others. Indeed, some participants felt certain family members had abdicated their
responsibilities by declining the test. Leslie described her brother's refusal to undergo testing
as cruel. She and two of her sisters had been tested and all three were found to be BRCA1
mutation carriers. Despite the family's extensive history of breast/ovarian cancer and now
information about a genetic defect, he refused to be tested. He had an adult daughter and
more recently, a “brand-new” granddaughter.
In Leslie’s words:

I think it’s very irresponsible. I mean if he doesn’t have it he doesn’t have to worry about worrying his kids about it. If he does, she’d [his adult daughter] better get tested pretty soon. It’s ridiculous. I think it’s very irresponsible, if you have something like that and you can, you know, make sure. ‘Cause I mean you’re giving your kid no option to have themselves checked, have themselves have any preventative stuff if they have to, or testing that they should have. It’s horrible. I think it’s very cruel.

These examples reinforce the realization that genetic information has implications for present and future generations, as well as how people understand the past. Testing creates a situation where the pursuit of genetic information by one person will automatically impact the choice of others. As previously shown, most participants saw this as beneficial and valued the opportunities it afforded them and others. Conversely, a few participants felt that their choice to know or not know was removed by these actions. And still others, like Leslie, viewed family members were being irresponsible by not seeking testing. She thought her brother’s refusal denied his daughter and grand-daughter the opportunity to better protect themselves. Ultimately, however, we see that genetic information is given meaning through relationships: past, present and future. Responsibilities are shaped by the perceived benefits or harms this knowledge might bring to oneself in relation to others.

Social self

In their qualitative studies, Geller et al. (1995), Murphy (1999) and Tessaro (1997) discussed altruism as an important facet in motivating some women to participate in genetic testing. Also embedded in participants’ narratives was a strong sense of altruism, “responding to known and unknown others in a self-transcending way” (Fox 1990: 207). Several participants expressed a desire to be tested, not just for their selves and their families, but for all women. They perceived a duty to do anything they could to advance medical
science. Women, who were affected with breast cancer, as well as those who had a family history but were disease-free, expressed this concern. Although an extension of the relational self, I use the term “social self” to describe this response. It allows me to make a distinction between actions taken with regard to family (known others) and actions take out of concern for society at large (unknown others).

Indeed, a number of participants described their decision to undergo testing not only for themselves or their families, but for the benefits it might afford all women. For example, when I asked Michelle whether she saw an advantage in genetic testing for herself, she summarized her feelings this way.

We sort of live like I’ll get it [breast cancer] anyway. So I guess maybe just confirmation or not confirmation, I mean maybe being given a window of hope I guess. But more, it’s not just for selfish reasons, it’s more for global reasons. Like if they can somehow use it to further cancer study or whatever. That would be a reason too.

Similarly, Claire perceived little immediate benefit from genetic testing for herself. She agreed to participate in testing only because she thought it might prove beneficial to breast cancer research. As stated previously, genetic testing for hereditary cancer began under a research protocol in Canada. Participants were aware that their test results were contributing to research as well.

The advantage is just information to the people doing cancer research. That is the only reason I said yes [to the testing]. The larger your sample size, the better your results...If our family is showing a lot of this, there is a good chance that we would have these genes that could help somebody’s research project and provide answers down the line for some other people, maybe even for us.

Ross also talked about the desire to contribute to research for the benefit of others. A family member had asked him to participate in testing because of their shared history of the disease. She had been found to be a BRCA1 mutation carrier. Initially, he was reluctant to
participate. His sister-in-law had recently died of breast cancer, and he just wanted to distance himself from anything to do with cancer. Despite his struggles with these memories, however, he felt an obligation to participate. He did not see the test of much use to himself, or his immediate family, but hoped his participation would benefit others. In his words:

I guess [I thought] if it could help, if it could help with a cure, or help their further their knowledge, that was a the reason to go....In my mind, I felt that the more they found out, the more they know, the more they are going to get to the bottom of it.

The concern displayed by these participants draws attention to the notion of relational citizenship (Gilligan 1982; Young 1990; Howson 1998). The latter is dependent on both social conditions and moral relations between individuals. Indeed, none of the previous examples fit into thinking about selves as isolated. Rather, it appears that these participants see themselves as moral agents, who wish to help society more broadly, by participating in research for known and unknown others.

**Reasons For Not Testing**

Having just explored the reasons why people undergo testing, I now turn to the small group (n=6) who declined testing. Four of the six participants were unaffected by cancer. Of these, three came from families in which a BRCA1 mutation had been previously identified in other family member(s). Three participants belonged to the same family (mother and two daughters). The mother and one daughter experienced early onset breast cancer (at ages 44 and 36 respectively). Their diagnoses, combined with their family history, made them eligible for testing but in agreement with the unaffected daughter, they decided not to proceed.

In this section, I explore how participants who refused the offer of testing accounted for their decision. Shaping the section are the following questions: Do those who decline
testing tell the same or different stories about risk and responsibility to others? What do they see as the choices facing them? Again, I found the categories of embodied self, relational self and social self germane to my reconstruction and analysis of participants’ responses.

**Embodied self**

The primary reason women gave for declining testing is that it would not alter their screening behavior or medical management. All six study participants recognized that their family and/or personal history put them at increased risk for cancer but felt that their current measures of health care surveillance were adequate. Like those who underwent testing they saw themselves as highly susceptible to the disease. Yet, this group perceived little or no benefit to from having genetic information. They told me that the information would make no impact on their embodied selves. Sheila put it this way.

We are very aware of it. It's not like it's taken us by surprise. I mean my mom has lived with it for over thirteen years and we knew about my aunt [died from ovarian cancer]. So for the last twenty years we've been very aware of it. And we I think we've taken the appropriate steps to not/1 mean yes to protect ourselves and also to know early on if there's anything...So this wouldn't change anything for me if I was confirmed that I had this breast cancer gene or this defected gene. It wouldn't change anything for me. It wouldn't change my life-style. It wouldn't change what I am doing. It doesn't change my predisposition to having the disease.

It doesn't do anything for me. It's, what is it, a confirmation? What do I need a confirmation for? My mom and my sister are enough confirmation for me. It's just another piece of information that I already have. Maybe it is a confirmation, but I don't need that. I can't do anything different than what I am doing. And from 12% to ninety percent [risk category] yeah there's a big spread, but I'm already assuming I'm in the ninety percent category. And I can't change anything.

Sheila’s comments illustrate that she is highly aware of her risk for breast/ovarian cancer. Further, she maintains that genetic testing would not make her *more* aware nor would it change what she is currently doing. Her explanation does not suggest complete rejection of medical authority or its technologies, however. Indeed, Sheila said that she follows current
screening recommendations. She does routine BSE, has annual mammograms and at the time of our interview had just begun ovarian screening. However, unlike those who undergo testing, she does not view genetic information as improving upon or changing her medical management. It would make no impact on her embodied self. Leanna, who had breast cancer at age 36, expressed a similar view. She did not reject genetic information per se, but questioned its utility for her.

I think for it to really be of value there’s got to be link in terms of being able to make a difference about the information. For instance I mean the PSA screening and stuff like that I mean at least that makes a difference. There there’s something there that you can do something about. With this there is really nothing you know you know you got this breast cancer gene, but what are you going to do about it? You should be doing your self exams every month anyway. You should be having your mammography once a year. You should be doing the [ovarian] ultrasound you know all those things you should be doing as part of just good health whether or not you have the gene or not.

These women’s accounts indicate that they did not reject a genetic mutation as the underlying etiology of breast/ovarian cancer. Rather, they did not seek testing on the basis it could not provide any practical benefit for them. Unlike those who sought testing, decliners did not think genetic testing offered them any further choice. They did not reject genetic testing outright but evaluated it in terms of the benefit it afforded them. Similar to those who were tested, they approached genetic testing pragmatically. One participant put it this way:

The genetic testing, I would sort of be willing to do it if they have something that could alter the genes or kill it or I don’t know do something. But they don’t know. They cannot at this point as far as I know/ there is no way that they could anything. It's just finding out that's it there.

One woman in this group, however, differed from the others in that she rejected the notion of hereditary factors as the underlying cause of the disease. Jordan felt that there was

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88 This may change in the future if studies continue to show that prophylactic mastectomy increases survival in BRCA 1 and 2 carriers. There is also some suggestion that tamoxifen might benefit BRCA2 carriers, although it does not appear to affect the survival rate of those with BRCA1 mutations.
not enough information to conclude that a genetic mutation contributed to the cancer in her family. She perceived lifestyle factors such as diet, the environment and smoking, as being more relevant to the development of the disease.

I don't agree with how, my mom especially, how she comes about with having this gene passed on, I don't agree with that. Because there isn't enough information to me. They felt that the cancer gene had been passed on to her through her father, and I'm not sure how that works. And they don't know how his parents died. And they suspect, although they cannot confirm it, that one of his sisters died of breast cancer, but nobody knows.

I don't understand how genes can be passed down, uh, you know, and how do we know these things? I don't / and how does a gene become mutated? I don't understand that either. You know I looked up mutated gene in the encyclopaedia and it said that a mutated gene could become mutated, the causes of it are mostly though things like radiation and, and that type of thing. I know my mom's background, you know, where she grew up. She grew up in a very high concentration of uranium in Northern Saskatchewan. And can you say that she was born with the gene or did the gene mutate because of her environment?

Jordan’s comments are astute in that she recognizes a gene does not mutate on its own. Even if an individual carries a mutation, something must cause the gene on the unaffected chromosome to mutate. This process is poorly understood scientifically. Yet, it is also important to locate this participant’s account within her general mistrust of medical technology. Despite her family history (her mother, sister and several aunts were living with or had died from breast/ovarian cancer) Jordan did not undergo routine mammographic screening or clinical exam. She also avoided having dental x-rays. She saw radiation exposure as a salient factor in the development of cancer and wished to prevent exposure at all costs. She maintained that environmental factors posed a greater risk to her health than did genetic ones. She saw no distinction between sporadic and familial cancer.

I also found that of those women who do get breast cancer, the majority of them don't have the gene. And so I / that's why I went with the environmental, pollution route because I feel that my chances of getting cancer are greater than, than if I had the
gene...And I feel that I'm doing what I would have done about it, whether I had known about a gene or not. So that's why I didn't want to go through the testing.

The mention of genetic testing in this context is somewhat confusing. Jordan dismisses genetic factors as contributing to cancer, yet at the same time she acknowledges the merit of the test by saying it would not alter what she does.

Treatment options

As previously stated, women in this group did not perceive genetic testing as offering them new choices. Namely, they did not view prophylactic surgery (mastectomy and/or oophorectomy) as an alternative or viable option. They had adopted all of the recommended screening procedures they were willing consider. Beth talked about prophylactic surgery as benefiting her cousins who were mutation carriers, although she had some concern about their decision. Yet, she wouldn't consider having the surgery herself. In her words:

Beth: I fully can understand for [cousin] why she did it. I mean I don't have any judgment on what somebody else you know any of them would do anyways. I do have some concerns. I have some concerns about you know my other cousin who's contemplating having the surgery just, but for her, if that's what she feels she needs to do then you know what / you know, we all have to do what will make ourselves feel the most comfortable. And if it is going to take the stress that stress away, then you know, go for it.

L: But what are your concerns about her?

Beth: I mean [it's] major surgery...For me I would consider it totally unnecessary surgery. I would avoid surgery of any sort at all possible costs you know. I would do every other alternative treatment whatever to surgery. I was, you know, I just don't feel like our bodies are meant for cutting-up (laughter). That's just you know that's how I feel.

Beth added that it was each person's responsibility to monitor her health and not seek medical attention at every turn. At the same time, she did not dismiss the utility of genetic testing altogether. She recognized that genetic information may motivate some people to attend to their health more closely. She, like the other participants, did not see genetic testing
in absolute terms but expressed some ambivalence. Indeed, Beth was aware of her
ambivalence, admitting that she felt differently about genetic testing on different days.

I have mixed feelings about the whole idea of genetic testing. I mean in some
instances, it's you know it's a positive thing in that I think people then who thought
that they, you know, who take the attitude that I can do what I want you know, I am
not going to be affected, may be will look at what they are doing in their life you
know and how and how they are looking after themselves. They do have a
responsibility to a point for their own health. But you know it also opens a can of
worms where you know how much / who gets the information, how hysterical they
may get about it. So I'm, I'm yeah I'm a little bit you know I'm. I don't know. I don't
know. Different days I feel differently too.

In addition to being of little practical use, all six participants declined genetic testing
on the basis that it would cause them increased anxiety. Instead of providing information that
would enable them to take action, they saw genetic testing as potentially distressing. With the
exception of the Jordan, most did not question the veracity of medical information. They
were similar to participants who sought testing in this respect. Yet, rather than adhering to
the notion that information is power or that it is better to know than to not know, decliners
perceived genetic information as something that would adversely affect their lives. Learning
their carrier status did not offer the promise of control, but posed a potential risk. Women
with breast cancer as well as those who were unaffected by the disease, expressed concern
about the impact a positive test result would have on their emotional well-being. The
following comments help illustrate this point.

Counseling kind of established that there isn't really anything you can do about it... right? That it's important to maintain that the level of you know the mammogram and all that stuff... right? ....It didn't seem to be information that was going to, that you were going to do anything about to make it any better, so why find out about it to make you feel worse. (Participant affected by breast cancer)

If I find out that I have that gene, I would be more worried to know that I have it because then I say well I am more susceptible to getting it. So, I think I worry about it enough (laughing). I worry about it enough yeah. (Participant affected by breast cancer)
I am sure there are millions of people walking around with the gene who don't know it or who do know it and it doesn't affect their life. Like you think it might be something gene testing might be something that might swallow a person's thoughts up, you know because they know they have the gene for cancer and then they just sitting waiting to receive cancer and then cancer becomes this consuming thing in your life. I don't really want that you know. (Unaffected participant)

At this point in my life, is it going to do anything for me? NO. Is it going to maybe give me one more preoccupation? Maybe. And I don't need that. I mean it's / my sister's cancer is very recent and I don't know subconsciously if I've completely dealt with that. So I don't need anymore. I mean my subconscious is far too active as it is (laughter). I don't need to add to it...(Unaffected participant)

Psychological studies indicate that, for the most part, genetic testing for breast/ovarian cancer susceptibility has little impact on general levels of anxiety, distress or depression (Lerman 1996; Croyle, Smith et al. 1997; Coyne, Benazon et al. 2000; Schwartz, Peshkin et al. 2002). Those who test positive do not become more distressed and people with negative results are often relieved of anxiety. Yet, the comments above suggest that these studies may be based on somewhat of a biased group. Those who decline testing are the ones who fear distress if they test positive for the mutation. Individuals who believe that the information will be emotionally harmful are likely to self-select themselves out of testing protocols and thus not be represented in the former surveys. Indeed, genetic testing, for these women, will not "tame uncertainty" (Press et al 2000: 242) but rather create havoc with their emotional selves. They are different from acceptors in the sense that they did not see this knowledge as leading to better health. A positive result would engender their bodies as a source of danger and make them feel unsafe. This concern outweighed any potential benefit of learning they did not carry the mutation.

Lastly, like Jordan, some women in this group placed considerable faith in alternate forms of prevention. Diet, stress reduction, exercise and minimal exposure to environmental
pollutants were seen as significant factors in cancer prevention. Beth’s comments reflect this position.

I’ve always gone under the assumption that you know we were probably a high risk to start with you know and should live our lives accordingly. I try to you know eat well. Careful what I eat, don’t use a/I mean I believe in that there's a lot of environmental concerns. You know what you eat, what you breathe, the stress that you live under, I think those are the major factors. I mean the hereditary factors may be there more so for us than for anybody else, but I think how we choose to you know live our lives and look after ourselves is what will make the difference.

I believe vigilance is important. Diet is extremely important and the amount of stress that we take on. You know if we can learn not to take it on, then, I think that we’re at least getting somewhere, at least one step forward.

For this participant, choice lay not in the option of genetic testing but in how she lived her life on a daily basis.

**Relational self**

Having described how decisions to decline testing reflect practical concerns about the embodied self, I now turn to an examination of the relational self. Like those who had accepted testing, decliners did not discuss choices around testing solely as individuated or autonomous agents but also in connection to others. As previously stated, these participants saw genetic information as having the potential to cause excessive worry and emotional distress. Further, they perceived information gained from genetic testing as posing this risk not just to themselves but to other family members as well. Thus women who declined testing, just like those who accepted, sought to act in the best interests of themselves and their families in making their decision. Leanna described her concern for her sisters.

If you found out that you have it, then your anxiety level you know would just /especially if you haven't gone through it [cancer]. I mean for my sisters right? For me you know well I've been through it, but for my sisters who haven't been through it, the anxiety level would just I mean it would just / you would now be almost like a person who's been diagnosed with cancer because you're diagnosed with a breast cancer gene.... I mean I think / yeah if you have found out that you have the breast
cancer gene it would really be negative. It would be hard to distinguish the breast
cancer gene from breast cancer.

Reda, who did not have cancer, expressed a similar viewpoint.

You have this information that I don't know if you if you / if people should have. If
they know how to monitor it, you know? I think that you know a couple of members
in my family if they found out that they had the gene. I think it would just, like I am
really worried about my sister you know, because I think that if she found out that she
had the gene she'd panic.

Embedded in these comments is the ideology of genetic determinism. Those who have
mutation are destined to get cancer (even though positive results indicate a probability, not
certainty of developing cancer). Genetic counsellors go to considerable lengths to clarify this
misunderstanding, yet family history and experiential knowledge play a vital role in how
biomedical knowledge is understood. Recall that some participants viewed themselves as
pre-destined to get breast cancer, even though they chose not to be tested. It is important to
point out, however, that genetic determinism is not unique to this group but reflects a larger
social discourse that links genetic risk to inevitability. Indeed, many participants who sought
testing also expressed the view that a genetic mutation would eventually lead to cancer. Yet,
knowing whether they carried a mutation and taking action gave the latter hope, whereas “not
knowing” gave those who declined hope. They reached different decisions, but the two
groups of participants were alike in that they saw decisions connected to the well-being of
others as well as themselves.

Sheila, as well, declined testing out of concern for her children. She questioned the
impact that genetic testing might have on her insurability and eventually the insurability of
her children. Further, while they were too young to be tested themselves, she did not want to
burden them with the knowledge that she (their mother) could be at increased risk for cancer.
She said they had already suffered a lot from the recent death of their father.
Sheila: I don't want to know because I don't need the information and I think it would be just one more thing.

L: To deal with?

Sheila: To deal with. You know when you go to sign the insurance documents, you wonder whether or not you should have signed them as well. I mean I'm very aware of those types of things we do / I deal with this all the time and I guess I don't want to burden the kids with that either. They've lost their dad. They don't need to have confirmation that they have a fifty percent to ninety percent chance of their mom getting breast cancer.

Beth also saw insurance discrimination as a significant barrier to genetic testing. Like Sheila, she showed concern not so much for herself but for her children. At the time of our interview, they were 24, 21 and 18 years of age.

At this point I am kind of ambivalent about it [genetic testing]. And also the / I'm a little uncertain regarding you know the information the fact that the repercussions for future members of my family, say, or my children in regards to life insurance and that's a big one. That's a big one. You know I'm in some ways, in some ways I think it is opening a big can of worms... I mean I wouldn't be interested and I actually don't think any of my children would.

In stating her ambivalence, Beth's comment suggests to me that she might change her mind about testing if her children decided they wanted the information.

As previously discussed, women with young children frequently described their decisions to seek testing as influenced by obligations to their children. Participants were concerned with staying healthy and being able to care for particular others for whom they felt responsible. These women feared dying from cancer and leaving their children alone.

Likewise, those who rejected testing were also concerned about the well-being of their children. Yet, they did not view genetic testing as aiding them in this respect. Rather, they saw the test as inducing stress and yielding information that might harm themselves and also might harm their children.
Social Self

Although the small number of participants precludes me from drawing conclusions, only one woman who rejected testing configured her response in relation to responsibilities engendered by a social self. Most participants framed their decision to decline testing in terms of the neutral or negative impact it would have on themselves and their families. These women did not express the desire to aid medical science as a whole. Their response should not be too surprising, however, given that those who declined testing looked at the technology as having the potential to cause more harm than good. Indeed, Leanna was the only participant who discussed her actions in terms of social benefit. She explained her feelings this way.

I understand going through the process would add valuable information you know to research as part of the database and, but it's information that could potentially be negative in terms of your own feelings about yourself and your own emotions that you know and your individual needs you know at least from my perspective far out weigh those research needs when it really comes down to you. You kind of have to justify this and you feel bad about it and you feel guilty, but that's the way you feel.

Leanna's account describes genetic testing from a very different perspective than participants who expressed altruistic motives. Recall those who participated in genetic testing for the benefit of unknown others (society) viewed scientific research as leading to improvements that would ultimately benefit everyone. They perceived a duty to do anything they could to advance medical science. Leanna did not dismiss the importance of medical research, but declined testing on the basis that the knowledge would be detrimental to her. Leanna's comments point to another issue as well. Because medical research is largely perceived as a social good, some people may feel pressured to participate even though they are unsure about doing so. Note that Leanna stated she felt she had to justify her decision not to be a research participant.
It is also important to point out, however, that while she did not participate in research, Leanna said she tries to help women in other ways. She said that her breast cancer diagnosis has greatly increased her friends’ awareness of the disease and motivated some to get annual check-ups and mammography. She has also tried to support other women who are confronted with the possibility of having breast cancer. The following excerpt helps illustrate Leanna’s approach.

I had one really neat experience where I’m was doing a meeting with a group of team leaders, who are who are kind of supervisors in the area, and afterwards one of them came up to me...and she said, Oh she said, you know I’m going through the same thing that you’re going through...I have lump that that I am going to have a biopsy done on. And I said well you said you know majority of the times it’s nothing right, but it’s really good to follow it through. So I had sent her a little note about a week later because it was around about when it was going to be happening just to say you know I’m thinking of you and you know that kind of thing. And then I talked to her about two weeks later about some other stuff, but then she started talking about this -- because I hadn’t heard and don’t want you know, this is very private kind of thing, don’t want to pry. But she said that that day she had gone to the surgeon and the surgeon said Oh it’s nothing, and wouldn’t do the biopsy. And so she said, ‘well maybe I’m being paranoid you know, hypochondriac about this thing’ right and then she says ‘I got your note in my mail and I read it. I said to myself no, I’m not being a hypochondriac, no’ because she knew what I had done in terms of pursuing this thing right. And she went back to her back to her GP and she said you know this is what happened and the GP was really upset about it right, [he] referred her to the surgeon, and I think she’s getting it done in the next couple of weeks right. But that’s I mean those are the kind of the neat things about how they / that your own illness might help other people.

Leanna’s story helped me to understand that people use their illness, and genetic diagnosis, in a variety of ways to help others. Actions taken out of concern for social benefit are not restricted to participating in medical research alone. Nonetheless, women who refused testing differed from those who accepted in that altruism (the desire to benefit unknown/anonymous others) did not figure into their decision-making around genetic testing. Yet, it is quite possible that altruistic motives came to bear in other parts of their lives.
Summary

In this chapter, I set out to explore participants’ reasons for choosing or declining genetic testing. Participants’ accounts indicate that this choice is not just an objective activity based on an individual interest alone, but is a process that emerges and is constructed in relationship with others. Choices around testing involve decision-making about personal health, but also intersect with understandings of responsibility to children, extended family and unknown others. Further, an individual’s decision to be tested (or not) also affects the choice of others. As Evans (2001), Lerman (1997), Richards (1996) and many others have stated, what distinguishes hereditary disease from other disorders is their implications for family members. Indeed, within genetics, people may see their selves inscribed onto the lives of others. The reverse is also true.

The findings presented in this chapter also represent my interpretation of how decision-making about genetic testing involves an integration of different elements of moral self. These aspects of self refer to the manner in which participants viewed genetic testing when thinking about their own physical health (embodied self), their family’s health and well-being (relational self) and the welfare of society in general (social self). Although separated out for analytic purposes, clearly these aspects of self are not distinct entities but tightly integrated. Further, they are not static. Expressions of self, and accordingly the choices people make, may shift and change as circumstances within the family, relationships with others, or within one’s life change. Recall that Reda initially refused testing, although a mutation had been discovered in her family. At age 22, she did not see breast cancer as significant factor in her life. Over time, however, her view shifted from not wanting to know
to desiring information about her genetic risk. Cancer acquired more salience as she got older and subsequently Reda began to think that genetic testing might be useful to her.

Generally, most participants talked about genetic testing as providing choice. Some people valued genetic information both for the sake of knowing and for the control over their life that this knowledge implied. Others hoped to put uncertainty to rest. Some wished to lessen their worry or to avoid surveillance programmes if they were to test negative. In this sense, genetic testing was seen as enabling regardless of who initiated it. At the core of these accounts were women who perceived cancer as a tangible threat to their embodied selves. They accepted the privileged discourse of science because it responded to a place where they felt threatened. That does not mean they did not feel constrained by the options available, but genetic testing held out the best hope for improved survival. In other words, they approached genetic testing pragmatically. This response is not unique to genetics, however. Focusing on the complexity of women’s relationship to medical technology, Lock and Kaufert (1998) have written: “For by force of the circumstances of their lives, women have always had to learn how they may best use what is available to them. If the apparent benefits outweigh the costs to themselves, and if the technology serves their own end, then most women will avail themselves of what is offered” (p. 3). To this end, I have argued that most participants did not acquiesce to genetic technology unwittingly; rather they were trying to resist this disease in the best way they thought possible. At the same time, I recognize that some women embarked on testing without giving it much thought.

For a few participants, however, genetic testing by others denied them the opportunity of choice. These participants stressed the familial implications of genetics and felt that this

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89 This kind of constraint is not unique to genetics, however. In the normal course of medicine people have to deal with difficult options. For example, a patient with cancer would not 'choose' to undergo surgery, chemotherapy or radiation therapy if this was not seen as providing the best opportunity for survival.
information (and accordingly, its burdens and benefits) was thrust upon them without their consent. Still other women, who came from high risk families, decided not to seek testing. They did not challenge genetic information, for the most part, but felt constrained by the narrow range of medical options available to them. They declined genetic testing on the basis that it would not change their medical management. As well, they feared the results of testing would be emotionally disturbing.

While participants’ choices around testing reflected practical concerns about the embodied self, the self in relation to others was also instrumental in making these decisions. Participants considered genetic testing in relation to the welfare of the family and their responsibilities to specific others. Some women believed testing could give their daughters, sisters and other female relatives information that would be useful for them. Others, referring to their own experiences with breast cancer, hoped that genetic information would allow family members greater control over the disease. Still others, acquired genetic information with the hope it would allow them to fulfill their role-based (parenting) responsibilities. Many also expressed a desire to aid other women and society in general. Similarly, those who declined testing voiced concern about the impact that this information would have on family members. They also felt responsible for their families, but thought that a positive result would do more harm than good. They perceived the family as a unit and felt a responsibility to that unit. What this suggests, then, is that we should be careful about dichotomizing decision-making around genetic testing into accepters and decliners.

Very few studies have examined factors influencing patients’ decision to decline genetic testing for hereditary cancer. This population, by the very nature of their refusal to be tested, is quite difficult to access. However, one study from the U.S. (Geer et al, 2001) showed similar findings in that emotional impact on family and no perceived benefit were cited as reasons to decline testing. However, more important in shaping patients decisions were the “concern over health insurability for self or family and cost.” Although a few participants in this study expressed concern about life insurance, this situation highlights the significant differences between the U.S. and Canadian health care system. It draws attention to how social, economic and political contexts influence the choices made about genetic testing.
the outcomes differed, participants drew upon similar aspects of moral self in making their decisions.

To conclude, genetic testing is enacted within discursive practices (medical, ethical and legal) that give primacy to individualistic models of autonomy, rational decision-making and choice. Yet, this study suggests that a relational concept of self provides a better framework for understanding some of the complexities raised by genetic testing for hereditary breast/ovarian cancer. Participants did not view their decision to seek testing in isolation from everyone else. Rather, obtaining genetic information allowed them to express their identity as embodied selves as well as “selves-in-relation,” (Held 1993), that is as mothers, daughters, sisters, fathers and citizens. Choice did not appear to be ‘autonomous’ in an individualistic sense, but existed along a continuum of self-care and concern for others. Particularly noteworthy is how the decision to pursue genetic testing reflected a choice defined and made within the context of family and community. Moreover, this choice has implications not just for the individual, but also for past, present and future generations.

This chapter provides my interpretation of how women/men construct their decisions to accept or decline genetic testing as an expression of self and moral agency. With this groundwork laid, I now move to an exploration of the impact genetic test results (both positive and negative) have on participants’ senses of self and moral identity.
CHAPTER SEVEN:

Genetic Testing and Understandings of Self

In ordinary life, we maintain the fiction that while circumstances change, character is constant—that whatever we do, our essential, core identity remains the same. This fiction has a lot of truth in it, of course, but it is also true that over time our characters can change dramatically.

--- Carl Elliott, *A Philosophical Disease: Bioethics, Culture and Identity*

Listen. To live is to be marked. To live is to change, to acquire the words of a story, and that is the only celebration we mortals really know. In perfect stillness, frankly, I’ve only found sorrow.

---- Barbara Kingsolver, *The Poisonwood Bible*

Introduction

In the last chapter, I described how people are motivated to seek genetic testing out of self-care, as well as concern and responsibility for others. I suggested that choices we make are not just abstract obligations, but intersect with understandings of self. The participants’ accounts also reveal, however, that responsibility engendered by genetic testing can lead to coercion. In particular, mothers who have been afflicted with breast/ovarian cancer or those who have experienced the trauma of family members dying from the disease, may pressure daughters to be tested out of concern for their well-being. Thus while we speak of genetic technology as providing choice, it is important to attend to what this concept actually means in the context of peoples’ lives. It is also important to remember that choice is not a purely
subjective act (Smiley 1992). The categories and concepts we use for evaluating choice come from a social and political context that defines choice in certain ways.\footnote{There is a wide and diverse body of literature that addresses this point. See Smiley (1992), Walker (1998), Sherwin et al (1998) as a few examples.}

This chapter seeks to extend the understanding of genetic testing by exploring what it means to be identified to be at genetic risk for breast/ovarian cancer (or not). Shaping my analysis are the following questions: How do participants understand genetic test results with respect to their sense of self and moral identity? Does knowledge of genetic risk (positive or negative result) affect people’s understandings of agency, choice and relationships with others? Does it change the way participants think about themselves or their families? Again, I am interested in the moral responsibilities created by this kind of information. For example, participants spoke about pursuing testing not just for their own benefit, but the benefit of the whole family. Who then takes primary responsibility for communication about, and translation of, genetic information within the family? Does disclosure of genetic risk information impose particular burdens or benefits?

The chapter is divided into five sections. Expanding on the themes identified in the last Chapter, I further explore participants’ accounts through elements of self. I begin by looking at the impact of genetic test results on participants’ perceptions of their embodied selves. In the second and third sections, I explore the intersection between genetic test information and the relational and social self respectively. The fourth section takes a somewhat different turn by examining concerns raised by genetic test information in relation to stage in one’s life. As feminist scholars remind us, women do not speak in one voice but many (Meyers 1997; Mitchinson 1998; Sherwin 1998). I hope that an examination of this area will help illustrate how “situated knowledges” are integral to the understanding of
choices raised by genetic testing. (Haraway 1991). The last section provides a summary of
the findings.

In order to situate what follows, a few quantitative details are useful here. As shown
in Table 6, 39 participants received genetic test results for hereditary breast/ovarian cancer.
Of this group, 14 women had already been affected by breast/ovarian cancer and 25
participants (20 women, 5 men) were unaffected, but eligible for testing based on family
history or the existent of a known family mutation. Of the 14 women who had breast cancer,
13 tested positive and one was negative for the BRCA 1/2 mutation. The unaffected group
(n= 25) portrayed a more even ratio in genetic test results: 15 tested positive (12 women, 3
men) and 10 were negative (8 women, 2 men).

Embodied Self

This section explores the intersection between genetic test information (positive and
negative results) on conceptions of the embodied self. Based on participants’ accounts, I
differentiate the embodied self into four broad categories: the aware self, the safe self, the
risky self and the uncertain self. Three of these categories -- the ‘aware,’ ‘risky’ and/or
‘uncertain’ self – pertain mainly to mutation carriers. The ‘safe’ self applies to those who
received positive and negative results. Before proceeding further, however, I wish to offer the
following caveat. My constructions of the embodied self reflect participants’ responses to
their test results at one point in time. I suspect that the experience of genetic testing is not a
static process, but one that involves changing perspectives. It is quite possible, for example,
that participants’ views might change as they live with this information longer, as other
family member receive test results, or if they and/or other relatives develop cancer. This in
turn will impact their sense of self.
Table 6:
Genetic test results: breakdown by cancer status

<table>
<thead>
<tr>
<th>Participant profile</th>
<th>Females</th>
<th>Males</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive test results: affected by cancer</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>Negative test results: affected by cancer</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Positive test results: unaffected by cancer</td>
<td>12</td>
<td>3</td>
</tr>
<tr>
<td>Negative test results: unaffected by cancer</td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>34</td>
<td>5</td>
</tr>
</tbody>
</table>
Aware self

For the vast majority of participants who tested positive for BRCA1/2 mutations, their results did not come as surprise. Rather, the discovery of a mutation related to breast/ovarian cancer confirmed something they knew through empathetic and/or embodied experience. Lucie’s comments were quite typical in this regard. As far back as she could remember on her father’s side (three generations) “every woman has died of it [ovarian cancer] in the family.” Lucie, however, was the first woman in her family to develop breast cancer. She was affected at age 35.

I, in my own mind, knew that it was, you know, it was being passed down somehow, and I knew I had the gene. And it just seemed like it was a strong gene that was being passed down, it's not skipping anybody so far. It didn't bother me at all. I knew it was there. I'd rather know it was there, and okay, let's deal with it, you know, let my doctors know and everything else, so we do the best we can. I've just had my ovaries removed. And, to me, that's the best I can do right now. Take my chances down, and now we just watch and, hopefully, if something does happen, we catch it early enough. And then I go on with my life without worrying about it.

Many participants linked their positive results to becoming more aware of their embodied selves. Similar to Lucie, they already considered themselves at risk for breast/ovarian cancer but testing provided medical certainty and a biological basis to this risk. Carriers saw genetic information as making them more “aware” of their risk and knowing what to look for. Knowledge of their genetic status, coupled with surveillance measures, provided them the possibility (in partnership with their physicians) of managing their risk. In this way, it enhanced their agency. The following accounts help illustrate this point.

I am happy that I went through with it [genetic testing]. I mean rather than just going along merrily and then all of a sudden you know you’re forty years old and boom you know you've got breast cancer and it spread... right? So I'm glad you know now we are top of it and if anything if it does develop is to catch it quick. (Unaffected participant, mutation carrier)
For me, you know as scary as it was to sort of say hey, this is in my family and now I am carrying this gene as well and it has increased my risks, the flip side of it is that I would have never known. I might have found out about the family history, possibly, but how seriously I would have taken that I don't know. Would I be involved in this early screening that seems to be extremely thorough? No. I wouldn't be. It would just sort of me relying on myself and my annual checkups from my doctor probably... The self-screening that I do is obviously 100% more than before. Because before, I really wasn't doing anything... I never used to really pay attention to it, so the awareness has increased a lot.

(Unaffected participant, mutation carrier).

At least you're more aware, right? I mean even if you don't do it [prophylactic surgery], and you find out you do carry the gene, at least you're that more aware that, you know, to make sure that you check yourself and just watch what you're eating and, even though that has nothing to do with it, but, you know, try to stay as healthy as you can (Affected participant, mutation carrier).

These participants' interpretation of their genetic test results reflects a broader medical and social understanding of cancer. Indeed, the notion that early detection is the key to successful treatment is embedded in both medical and public discourse. Commonly heard is the message that early diagnosis promises less invasive, less costly interventions as well as a better chance of survival. Genetic testing fits into this discourse by increasing awareness and offering the possibility of even earlier detection. For example, Chris learned that she carried the same mutation as her mother. She is not considering surgery, but said that the test results have prompted her to be more vigilant about breast screening. She now does monthly BSE, which she did not do prior to genetic testing, and has mammography twice a year. She sees early detection as the main advantage to her, and feels that it is "better to know than not know." John, whose daughters inherited BRCA1 mutation from him, put it this way:

Early detection. Early detection is necessary for immediate remedial operations or whatever is required and the chance of immediate remedial procedures increases your life-span considerably. Because once it gets into your lymph glands and gets down to your liver you're a dead duck. Gets into your blood system and gets going / probably end up in your brain, in your chest or something like that. That is a real advantage of the genetic testing because you're forewarned to keep your eyes open, or the doctor to
keep his eye open for something that's out of the ordinary. That's where the advantage lies.

At the centre of these accounts are people who are willing to engage in medical surveillance if it will enhance the possibility of early detection and their long-term survival. In a parallel fashion, awareness of genetic risk led most mutation carriers to consider non-medical (lifestyle) approaches to managing risk such as changes to diet, exercise and stress. At the same time, not all participants who tested positive believed that their genetic results predicted a single fate. While Chris understood that her positive mutation status put her at higher risk for developing breast/ovarian cancer, she emphasized that those who test negative should continue to screen themselves as well. No woman was risk-free.

I just have to wait and see and who knows? I mean it, I can maybe never ever get it, there's still that two percent chance that I might not. And there's still the fifty or whatever percent chance my sister might when she doesn't have the gene, so I mean, as far as changing my outlook on it, I don't know. I think she should still check herself just as much as I do. I think everybody's still got a really big opportunity of getting it. I've just got more, I guess you don't want to say opportunity, chance of getting it. I've got more of a chance, so it's good to know. It's really good to know.

Safe self

Positive Results

Closely related to the aware self is the safe self. For many participants in this study, the risk of breast/ovarian cancer had a profound and even limiting effect on their lives. Some described their anxiety about developing cancer as all-encompassing at times. Others could not imagine a future without cancer. And still others, described their breast/bodies as "time bombs."92 Women who had been breast cancer patients, as well those who were cancer-free, said that genetic testing gave them the opportunity to confront their fears. Once they knew

92 The description of breasts as "time bombs" has also been reported in other studies. See Burke et al, (1997), Hallowell (2000) and Robertson (1998).
they were at genetic risk, the threat of cancer was something that could be dealt with and
possibly overcome. For these women, genetic information was instrumental in guiding their
decision-making about medical intervention (increased surveillance or prophylactic surgery)
that might make their bodies safe. The following excerpts illustrate this point.

P: Genetic testing to me is the best thing that ever happened. It's a miracle, it's been
so good for my life. I've moved ahead in these last three years like I never dreamed I
could because I didn't have that fear of death hanging over you know like looming
large. You get a pain here, you get a pain it's like Oh, it's probably bone cancer. Oh, it
could be this and it could be that. I'm a cart before the horse person you know. If I
can find out what is / what the possibilities are in the offing and there is something
that I can do about it, I like to take care of it before I get there if I possibly can. Now
for me this has been the best thing, the best thing that's ever happened is this
knowledge for me because it just freed me. It freed me so completely...
L: Did you find yourself checking all the time and this sort of stuff?
P: OH, ALL THE TIME, made myself sick. (Breast cancer patient, mutation
carrier)

To me, it's a safety factor. I mean, if it's, if we have it, whether I have/be tested or
not, it's not going to make any difference -- I have that gene. Let's take my best
chances with it. Now what can I do? I can have my ovaries removed or
hysterectomy, whichever, you know, [is] best for me. (Breast cancer patient, mutation
carrier)

Now having taken the test and being at that state of mind and finding out that I did
have the BRCA1 gene, and also to be able to have taken the precautions of taking out
my ovaries and not having to worry about them - I guess it's sort of like
I take a more, a more optimistic outlook on it - it's sort of like, um, you've been,
you've been sort of given a gift - you know a gift of, of an advanced warning - be sort
of like, you know the doctor comes and says, well you've got this little ulcer in your
stomach, and we could take it out right now before it you know it grows and it
becomes hurtful to you and takes you through a lot of agony and pain and stuff, or we
could leave it there. (Unaffected participant, mutation carrier)

I'm still happy that I that I found out and got the results and that I can actually do
something, you know, to be preventative. And, I think it's a good thing. Maybe not
for everybody, but I think for a lot of people. (Unaffected participant, mutation
carrier)

I don't have to worry anymore about do I have hereditary cancer? Am I going to get
it? I know I'm [at genetic risk for] hereditary cancer and I've dealt with it. It put me
in a position where I could meet it head on and, and not make it a foremost thought in

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93 I use upper case letters to denote the participant's emphasis on certain words.
my mind. [Before] you're always aware, you're always, it's always there. You're always confronted with it. You feel a little bit of a strange lump you're worried, right away, instantly, because cancer is so prevalent [in my family]. And this has given me the opportunity to, um, well, it's just made/ it's just allowed me to deal with it and have it done with, instead of waiting for it to get me. I beat it. Just in a different way.... It's made a big impact on my life. But I think/ I feel blessed. I feel like it's a bonus. (Unaffected participant, mutation carrier)

I just can't imagine not wanting to know, or not being able, not wanting to deal with it. I'd have to say that just about for everyone in our family. I mean it's the shits when you're positive, but to not know and just go along I mean what are your choices? They're much worse. (Unaffected participant, mutation carrier)

These passages indicate that some women used their test results to confront their cancer risk. At the site of the individual body, genetic testing was seen as enabling, a resource which could be used in defense against cancer. Genetic testing provided the basis for participants to seek certain interventions or increase surveillance in hopes of improving their chances of survival. It also impelled them to address life style factors (diet, exercise, stress reduction strategies) in an attempt to lessen their risk. Critics have warned that genetic testing will result in the increased medicalization of women’s lives (Lippman 1998). This is true, but most participants aimed their resistance at the disease rather than at medicalization. If medical technology would help them they would use it. Indeed, for one woman, prophylactic mastectomy (based on her positive carrier status) resulted in the detection of a small ductal carcinoma in situ in her left breast. Her previous six month check-up had shown her to be cancer-free. “I said [to the surgeon], I just had my checkup, how long would it be before that showed up? She said “5 to 8 years.” So you know, I was looking at a life expectancy of 60 on a good day.”
This group of participants used their positive genetic test results to achieve their own objectives, that being increased safety. Some spoke about the desire that it had been available sooner for other relatives. Lorraine, a mutation carrier and whose mother died of ovarian cancer, said: "If that test had been available, I know my mother would have had it and if she had tested positive she would have had her ovaries out. So it's really unfortunate. But now that it's available certainly other people don't have to not act." At the same time, most did not look at themselves as totally risk-free following prophylactic surgery. They knew that mastectomy reduced their risk of breast cancer to that of the general population and oophorectomy did not offer a panacea. Some participants also raised the point that testing (and medical intervention) did not eliminate their risk for other diseases; yet they felt safer as a result of their choice.

Genetic testing enabled women to improve their safety in another way still. Two participants said their positive results allowed them to get access to services they were previously denied. These women saw themselves at significant risk for breast cancer because of their family history. Yet, their physicians did not refer them to mammography, or did not take their concerns seriously, because of their age. Both were in their twenties at the time.

The following quote illustrates Leslie’s frustration over this.

Leslie: I had a lump in my left breast when I was twenty-two and had to fight and scream, here in [city], had to fight and scream to get mammograms done, and then it was another big to do just to get the damn thing taken out. And then six years ago I had a big lump in my right breast. I had to go through the whole nine yards all over again and then the surgeon didn't even want to take it out. Knew about my family history and I told her/ it got down to the point where if they didn't take it out I was

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94 While this group of participants underwent genetic testing readily, I do not wish to minimize the difficulty of making decisions once they were found to be mutation carriers. As one participant put it: "It is really big ... you know, something that's big in your life, you have to deal with. But it's not as big in your life to have to deal with as cancer is." Another person expressed similar sentiments when I asked her whether genetic information changed her life: "Oh, for sure...you're gonna have to make some decisions and, and do something, either to do nothing or to do something, but it definitely is going to make you put a lot of soul searching into the future."
going to take it out. That was the only way I could convince them that I wanted it gone. Now it's easy. After I had the testing done I found my lump in Easter, called up my doctor's office and she wasn't going to give me an appointment, and I just, well you / you talk to my doctor and you find out if I'm going in or not. I was in right away. Had my biopsies right away, had my results right away. Had the mammograms right away. No problems.

L: Just because of this genetic test?

Leslie: It gives me something to back myself up with. I'm not joking around, I'm a confirmed gene carrier. So instead of just saying, oh, you know, I have a lump, I don't know. Yeah, it's been a lot easier. Way better.

Liz shared a similar experience.

Liz: I've always been precautious and getting checkups and if anything now with this [positive genetic test result] I think the doctors are more for me getting tested. At first they wouldn't give me mammograms. I ended up changing doctors because the one he refused because I wasn't old enough he said.

L: Even with your family history?

Liz: Yes, yes. So I changed and I think now, like I said I have the more thorough testing now [after receiving positive results]. They okayed it, I guess you could say.

These excerpts suggest that women use their genetic test results not only to plan their medical management, but also to confront the medical authority if necessary. Despite family history, their physicians failed to refer them onto certain services because of their age. In each of these situations, however, the genetic test results increased the legitimacy of the participants' claims. It allowed them to challenge medical notions about the typical breast cancer trajectory. While it is troubling that their physicians gave so little import to their concerns and family history, genetic testing provided them with the means by which they could take better care of themselves. They used their test results to challenge authoritative knowledge and medical networks of power.

Recall that breast cancer is a disease that primarily afflicts women over the age of 50; moreover, the benefit of mammography and other surveillance methods is equivocal in younger women.
Negative results

As other studies have shown, participants described their negative\textsuperscript{96} test results as greatly alleviating their cancer anxiety. Susan, like many other participants, grew up in a family beset with cancer. Her mother and maternal aunt had been afflicted with breast cancer at age 30 and 41 respectively. Her maternal grandmother had died from ovarian cancer at 56 years old. Susan’s sense of vulnerability began to increase as she neared the age when her mother first developed cancer. Indeed, she questioned whether she should have children because of her family’s cancer legacy and recently discovered mutation status (both her mother and aunt tested positive for a BRCA mutation). The following remarks help illustrate the relief she felt in testing negative.

I still think about [cancer] just because I know it that doesn't mean I'm never going to get it. I just have as much chance as anyone else who doesn't have the gene. But I feel more I guess normal whatever normal is just because I don't have [the genetic mutation]. I always thought for sure I'd get it [cancer] just because of the family history. I thought that that's how it went. I was relieved that I could just kind of relax about it. I am still aware. I still you know, check and I try to eat more healthy... I've always kind of thought that way, but right after I was [tested] you know thinking that way more because I felt like I got a second chance. I better keep it up make sure nothing bad happens to me, just a psychological thing... I watch [T.V], but it's not the same. I don't have to stop everything I'm doing come/ run into the living room and sit and listen and make sure I don't miss anything. I'll watch it (if) it's interesting to me. I'm just not as worried about it or scared.

Susan’s comments remind me that for some people, familial cancer serves as a constant backdrop to their lives. It is a shadow that is always there, affecting how they live, what they eat, what they watch on T.V. and sometimes what kinds of relationships they are willing to entertain. Susan, like participants, recognized that a negative result did not completely

\textsuperscript{96} It is important to point out here that participants who tested negative were true negatives; that is, they did not carry a previously identified family mutation. It is likely that the responses of this group will be quite different from those in which a BRCA mutation is suspected based on family history, but has not been found on testing. For the latter group, a ‘negative result’ is not considered a true negative but inconclusive. Christine Maheu, a Ph.D. (c) in the School of Nursing, is studying the effect of testing in families where results are inconclusive.
eliminate her risk for breast/ovarian cancer. Rather, it just reduced it to that of the general population. This, in itself, made her feel safer. She was more ready to accept whatever else might occur.

Jan also spoke of her negative test results as relieving her of a burden. Her mother had breast cancer as did her grandmother, her maternal aunt, her maternal aunt’s daughter and two of her cousin’s daughters. When her mother died of complications from the disease, her fear of cancer began to overwhelm her. She saw cancerous cells growing in her breast and stopped doing regular self-breast exams because she was so afraid that she would find a lump. Her negative test results came as both a surprise and a huge relief. Nonetheless, it took Jan some time to actually believe that her future did not include hereditary breast cancer.97

What was I trying to say? Whether I believe it now? Yes. Because the one thing that has changed is what/why I realize now is that my chances of having breast cancer go from one in two to one in the general population, eight, which is still a lot. [Up until recently] I had steadfastly refused to think about hormones in any form and I still wouldn’t take hormone replacement therapy, but I did ask my doctor for some estrogen cream, vaginal cream because I had a dryness problem. So that felt like, I don’t have to be quite so very careful now. I can take this one, little tiny risk and have more estrogen in my system. So that was a sign to me. It took me a long time, several months to think about that and to realize OK I could do this now, as a sign to me that I let go of thinking that I do have the gene.

Martha,98 who had already been afflicted with breast cancer, expressed a different sense of safety. Prior to testing, she was very concerned about getting a new primary or recurrence and what that meant to her survival. Although she realized she still may get cancer again, 

97 This observation is not restricted to hereditary cancer. In a study of linkage testing for Huntington’s Disease, Codori and Brandt (1994) reported that up to one-third study participants initially expressed “disbelief” in testing results. After living with the risk of HD for so long, their test negative results did not “sink in” for a month to even years after receipt.
98 Martha met testing criteria because of her Ashkenazi Jewish heritage, not because of a strong familial pattern of breast cancer. Her mother and aunt had breast cancer at post-menopausal ages and both were successfully treated. Martha had breast cancer at age 50, which by itself is not considered an indicator for hereditary disease.
testing negative has given her hope. The knowledge that she might get cancer as a result of her age versus genetic inheritance has greatly reduced the intensity of her fear.

Martha: I continue to feel lucky. Lucky that, that I have this information. Because now I know that, you know, I might have breast cancer again in my life. If I do, it's just because. And that my sister might have it, my niece might have it. But it's just because. Their risk is not higher.

L: And that's reassuring to you?

Martha: That's very reassuring. Very reassuring. In fact, it sounds odd, but because I got breast cancer at fifty, it won't be a very big surprise if I get another site in my life span. There is confidence, because of the medical system, that that's okay. It's no fun. It's definitely no fun, but it's okay.

L: You'll be taken care of?

Martha: I'll be taken care of, and it's not going to really challenge my survival. It's not going to kill me. I'm not/it will be safe.

By offering a different framework for understanding breast cancer, genetic testing shaped the way Martha saw her past cancer experience as well as any future experiences with disease. Martha believes that if she gets breast cancer again she will be safe. It may challenge her survival, but as something that older women get. Martha's comments imply a strong sense of genetic determinism; that is she viewed a positive result as condemning her to a dire future. In her words, if she were found to be a mutation carrier it would be the "beginning of a downward spiral." In contrast, she saw sporadic cancer (cancer due to age) as something that could be managed. Interestingly, her family experiences did not support this interpretation; both her mother and aunt had breast cancer at an older age and responded well to treatment. Rather, it was her experiences as an oncology nurse, and witnessing the unfavorable outcomes of hereditary cancer families, that led Martha to this view. Likewise, another participant affected by cancer explained how knowledge that she carried a BRCA1 mutation caused her to look at her cancer differently.
I am not sure if I would have made those same decisions not knowing that I was/ that I had the gene. You know then I might have just taken my risks/just had the lumpectomy and the lymph nodes removed and all the treatment and maybe just waited and prayed. But when you know that you have the genetics there and that at any point that gene could fire up and start producing again it's like different.

Critics, as well as others, have raised the particular concern that women who test negative may be falsely reassured; that is they may think they are at no risk for breast cancer, and stop screening measures altogether (Hopwood 1997; Carter and Hailey 1999). Contrary to this concern, most participants recognized that a negative test did not eliminate risk altogether. Only one of the 14 participants who tested negative suggested otherwise. Julie said after worrying about cancer for most of her adult life, she dropped her screening regimen after receiving her negative test results.

Actually it made me feel I guess safe for awhile, like I thought I was well I'll never get it now sort of thing. You know you sort of get into a safe mode. Oh I'm okay now. I won't get it, that's basically the way I was thinking then.

I asked her to explain this further.

Julie: I sort of thought well I don't have nothing to worry about now... Don't need to go to the doctor for checkups don't need to this, don't need to do that. It (laughing) got me a little TOO safe mode I think.

L: Are you still in the same mode?

Julie: Oh I'm sort of coming out of it now. I'm going to go back and have check-ups and stuff. It's taken this long to get out of it [one and a half years].

Because she shared so many physical and behavioral traits with her mother, Julie felt destined to follow a similar life path. Her mother had died of ovarian cancer in her early fifties. Julie, like Martha, viewed genetic knowledge as deterministic. Freed from her perceived 'familial' burden, she initially reacted by dropping screening measures altogether.

Yet, she gained a broader perspective over time and talked about returning to her regular
check-ups. Julie’s account is instructive. It helps illustrate the point that people’s responses to genetic testing are not always fixed, but may change over time.

**Risky self**

Although not the predominant reaction, three participants experienced considerable distress after receiving positive results. Knowledge of their BRCA1-2 mutation status heightened their anxiety about developing cancer in the future. It led them to view their bodies as risky. They felt extremely vulnerable, troubled by both the certainty (genetic determinism) and uncertainty (their mutation status could not predict when their cancer might occur or how severe it might be) of genetic information. For two participants, this led to depression. Catherine’s account illustrates how her carrier status affected her sense of present and future self. She was 27 at the time of our interview.

It's like it's still hard, it's not that / it gets better. You ... learn to put things into perspective to try and use the information to the best of my or like to my advantage I suppose and also to keep in mind that that I'm not sick at this point and there are a lot of things to be thankful for just each day. It/ not that I was a selfish or greedy person, but people tend to go through life maybe not appreciating things and I think that it helped me to may be seize moments and to be more appreciative of what I do have. I mean there's a lot there's a lot of people that have it far worse than what our family does you know. It's not good news, it's not easy news, but it / you have to put that into perspective. I mean it's what it is. You can look around and start naming even people that we know that have situations that are worse. So you have to try and put it into perspective and I just try really hard to be strong because I thought if I let it get to me now I may as well have the cancer and be dying of some form of cancer if I am not living my life to the fullest now. I just took that attitude that I really had to gain control over my emotions and deal with it. But it / each day I don't think a day goes by that I don't think of it and some sometimes thinking well what am I going to do about it? Or sometimes panicking, you know, what's going to happen if? A lot of things in terms of my daughter spring it to mind. You know people talk about when she's this old or you know when she's this old and I think, Oh I hope that I'm here for that. You know I hope that I'll be alive and I find that hard. Lots of things with the future you know make me a little bit apprehensive or bring it to mind anyway that I certainly carry this risk. So it's definitely there with me. Just even you know little pains or something you'd feel that I don't think it's like your imagining it but just something really mild you tend to kind of focus on it if you had some kind of pain in
your breast or something you tend to you know or you get sort of over paranoid about things like that / it's like on a day to day basis, it's there.

Later in our interview, I asked Catherine whether genetic testing prompted her to consider things that she had not thought about previously. Catherine responded yes, and added:

Just dying in general. I don't think a lot of people in their late twenties sit and contemplate dying or leaving their husband and daughter that kind thing. Like I do think about it more than / certainly more than I ever did. I can't say I never thought about, it's not like I never thought about dying, but not on a day-to-day basis. I shouldn't say day-to-day, but even you know weekly basis, it wouldn't go through my mind the way it does now. But again like I go back to the to the question of do I think it's a good thing? I do. It might sound ironic to say after all that I've said, but because it is hard to know, but I think it's important to know. Not knowing is I guess you'd have the peace of mind in your life, which I mean there is a lot to be said for that, but I hope to get peace of mind that same peace of mind back I guess. And I've certainly come a long way I mean if you compare how I felt about this you know a year and a half ago to now / like I've come a long way.

Catherine's comments are especially troubling in that she lived in a small rural community four hours away from the nearest urban centre. Her town lacked the appropriate psycho/social resources to help her cope with her fears. With the exception of talking to her immediate family and a few close friends, she dealt with this on her own. I gave her my phone number and offered to connect her with social workers at the BCCA in Vancouver. I also let her genetic counsellors know that she was experiencing a lot of difficulty. She has never called me, and to my knowledge, her contact with the genetic counsellors has been minimal.

Marilyn, as well, talked about the difficulty of dealing with positive results. Although she did not hesitate to undergo testing (she described herself as “too nosey” not to), she now views her body as unsafe.

Lots of times I just think... yeah I've got this gene and I'm going to get breast cancer. Not that I'm being negative, but just that you know, a gut feeling like yeah I'll get it.

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99 This was done with the participant's knowledge of my actions.
Like it's a very high percentage. It's just, it's really scary to think that you probably will, like that you're...thinking yeah, I'm going to get it. Then the first thing you want to do is go and get a mastectomy done. But then the more I hear about it then I don't know if that's the way to go. It's not a hundred percent, but you feel like you're sitting like a ticking time bomb just waiting for it to happen.

Note that each of these participants did not perceive cancer as a disease that is preventable. Neither expressed much faith in screening measures (both breast self exam and mammography) nor really considered prophylactic surgery because of their ages (at the time of the interviews, Catherine and Marilyn were 27 and 29 years old respectively. Catherine was also pregnant). Further, they belonged to the group of “distant knowers,” in that they lacked personal experience with cancer. Catherine, for example, knew that her grandmother and other female relatives (from the paternal side of her family) had died from breast/ovarian cancer at early ages, but had never met them. As a result of genetic testing, however, her perception of breast cancer risk shifted from something vaguely known to be in the family to something embodied and quite scary. It threatened her survival, and in turn, her concept of present and future self. Marilyn had a similar reaction. Unlike participants who expected positive results because of embodied or personal experience, for these participants, genetic information conveyed a certainty of risk that they did not have beforehand. Expectations of a grim future had a profound effect on their sense of well-being and agency. It moved them from a state of health to impending illness and they perceived there was little they could do about it.

Kelly differed from the previous participants in that both her mother and an aunt had early onset breast cancer. Yet, cancer had been a recent development in their family; there had been no history of the disease prior to their diagnoses. Genetic testing, nonetheless,

100 Only a few participants viewed their bodies as ‘risky’ following genetic testing and they knew about their family history indirectly. However, the number of people who fall into this category may increase if due to commercialization, testing criteria are relaxed.
revealed the presence of a BRCA1 mutation, shifting their knowledge that breast cancer was something that occurred in the family to something that was hereditary. Kelly underwent testing and learned that she carried the mutation as well. When I asked her how much did she think about her cancer risk, she responded:

You think about it a lot. You think have I done my breast exam this month or not? And when you do it you think about it, and like even this [swollen] lymph node in my neck ... I started thinking, well, you know, probably not good that I have a lymph node, and that's the way cancer travels and, and it sort of made me think, oh, uh-oh. And today when I found out I was pregnant, [my family physician] and I have been talking like we talked before that I should probably get a gynecologist in town. And I've been thinking well if I was pregnant and my breasts changed, how would I know if I had cancer? And so that's why, like we talked about me getting a gynecologist as opposed to a regular GP was so that I could have someone who maybe had a little bit more experience with that sort of thing.

Kelly, like Catherine and Marilyn, sought testing when she was in her twenties. All three accounts suggest that age, or more specifically life stage, may influence how genetic information is interpreted and used in one's life. I will explore this observation further in a later section.

Uncertain self

Unlike the previous participants, for some women/men the diagnosis of genetic mutation thrust them into an uncertain state. They did not see themselves as ill, but neither were they completely healthy. They did not have cancer, yet their positive mutation status conveyed a threat to future health. In comparison to participants who viewed themselves as 'risky' or 'safe,' participants in this group perceived their carrier status in more ambiguous terms. Their concern about cancer risk waxed and waned and tended to be triggered by certain events. Liz's response to the following question helps describe this observation further.

L: How much do you think about [your risk] for breast or ovarian cancer?
Liz: Not regularly -- I thought about it just on times like when [my sister] went and had her hysterectomy [oophorectomy].... when they took a biopsy of what they taken out/ if they’ve found any cells, I thought of it then. But I don’t think about it that often...I get my husband to do a lot of my breast checking as well, because I can’t get to certain areas, and I do have lumpy breasts as it is. So when he tends to work in an area a little longer than usual I start thinking okay what are you feeling? You know it’s a normal thing, but otherwise I don’t think about it everyday, not at all. Because if you did you’d go nuts.

Alice expressed similar sentiments. Living in a rural location, she said she mainly thought about her risk when making her appointment to attend the BCCA ‘high risk clinic’ in Vancouver.

I don't really think a lot about the gene until I'm in the Cancer Clinic, but it's just more the idea of taking the time off work and going to Vancouver. I think it's a great, obviously a great place to go. But you know, it'd be nice if it was/ there was one closer... because I've got to take two days off work. I mean definitely you, you think about it a lot more than normally when it comes time to go to the High Risk.

Alice’s comments suggest that distance involved in traveling to the high risk clinic posed an additional challenge for her. The necessity for surveillance, yet the difficulty in accessing services, made it difficult for her to manage her embodied risk. This, in turn, heightened her consciousness of her risk. While she did not have to travel nearly as far, Chris also said that she did not think much about her cancer risk until attending the high-risk clinic. For Chris, however, it was seeing people already affected by cancer that intensified her fear. Her concern subsided after she returned home.

Going to Vancouver was a little scary, going in the Cancer Clinic and seeing all these people with no hair and really sick and I'm standing there like, okay, there's nothing wrong with me -- yet. Right? So, that was a little discomforting. I didn't like that day. But it was a day. It's over with. I go back home, continue my life as it is.

Ross, a BRCA1 carrier, also talked about how his concern for cancer risk fluctuated at times. He initially underwent testing for altruistic reasons. His extended family was one of the first in B.C. to go through the genetic testing program. His cousin asked him to
participate and he did so thinking it would aid the research. He had sons and did not think the information had direct relevance to his family. Yet, his positive result came as a total surprise and created some uncertainty for him.

Some days you think about it more. If a friend is sick or somebody dies of cancer you hear different things, blink-like the light goes back on and Oh yeah, you know, oh yeah. A friend of ours, now he's my age [is] going in next week for a colon operation and that triggers it and like you think gee, you know, he's the same age as I am. A year younger than I am...So that, then it brings back yeah I got the gene, I got this positive gene, so you never forget it, it never goes away, but there's weeks on end months I don't even think about it.

Ross’s account suggests that genetic testing for the BRCA1/2 mutation may affect men more than might be suspected. Genetic services typically focus on women concerns because they are most at risk for developing cancers related to this mutation. Thus, men’s concerns may not always be addressed in a counselling session, leading to uncertainty about their health and future selves. Indeed, the following comments clearly indicate that he harbored fears about developing cancer as a result of his carrier status.  

I guess the thing that helped me most of all was when I went to my family doctor. He explained things very up-front and more than I was explained / not that [genetic counsellors/educators] weren’t extremely good, but he described more to me how that gene I have in me, not that how it can affect any other types of cancer, but the relationship between breast cancer and prostate cancer... he showed me the link, where the link is. So after talking to him, and him just saying look we'll just keep everything under control. We'll just do this, do this, do this, explained it, anything he said you want to know, anything I can help you with, you want to know, you're not feeling right with, come in and see me and we'll discuss it, we'll talk about it. If you read something, hear something that's bothering you about it, give me a call we'll get it straightened out. That made me feel I guess a lot better. I guess it just sort of settled things down.

Although I did not find any studies examining men’s perceptions of their carrier status, I found one report that examined men’s experiences in being in breast cancer families (McAllister, 1998). These investigators observed similar findings about cancer fear. Although not worried about getting breast cancer, men reported concern about being at risk for other types of cancer.

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Although not concerned about breast or ovarian cancer per se, Ross did not believe his carrier status left him risk free. Further, the lack of scientific information about whether or how this mutation might affect men likely contributed to his uncertainty. His brother, also a mutation carrier, was far more concerned what this mutation meant for his daughters than himself. Yet, he also expressed similar sentiments.

Because there isn't enough known about it, I don't want to start what I call awful-sizing on it and say well now that I've got it this is, but it does cross your mind. Like my brother said you know what don't they know may affect us, we may find-out ten years later that there is something more terrible about having this one gene. I don't know, but for now but not knowing you can't start letting your mind wander too much....I said well I got to fifty-four, maybe I'll get to eighty-four. Who knows?

While it does not preoccupy their thinking, these comments suggest that their carrier status left Ross and his brother with some uncertainty about their embodied selves. Unlike female carriers, men typically do not receive follow-up from genetic counsellors if they test positive for the mutation.

Sara said that she thought a lot about her genetic risk for the first month after she received her positive test results. She worried about the implications of her carrier status for her health and future. Since then, her concern has waned considerably although it resurges at times when she hears media reports about breast cancer.

I don’t let it consume me, I can honestly say. Probably when I thought about it the most was when I first found [out] the results, like say in the first month after. I was thinking about it a lot then. Frequency-wise, probably every day. Probably once a day, or twice a day you would start thinking oh gee, I wonder. Or else you would see something in the newspaper [about breast cancer], which there’s almost something everywhere you look now. So as soon as you’d see it, it would be like oh yeah, you know. Hmm, I wonder if it could happen to me? Or when will it happen to me or how bad will it be or that sort of thing? But that’s all kind of tapered off. I don’t think about it everyday now. I don’t let it.

These participants are similar to the previous group in that they did not view themselves as risk-free. At the same time, they did not perceive themselves as unhealthy.
There were periods of time when some participants did not think about their risk at all. Their mutation status put them into what some have called a 'liminal' state, that is a position of being neither ill nor perfectly well (Murphy, Scheer et al. 1988). Yet, I would argue this did not define the way they conducted their lives. Rather than feeling threatened, uncertainty coupled with pragmatism appeared to shape the way they viewed their embodied selves. These participants did not deny their genetic risk, but for the most part, accepted it as any other risk that needed to be dealt with. While worrisome at times, it became part of their awareness and part of their routine lives.

**Relational self**

Having described how genetic testing influences the way women and men think about their embodied selves, I now explore the influence genetic test results have on participants’ relationships with others. As illustrated in Chapter 6, participants rarely considered genetic testing in terms of themselves alone, but rather as selves in relation to others. Receipt of test results evoked a similar response. Repercussions were ongoing, not just in terms of information disclosure, but how it affected relationships, commitments and responsibilities to others. In what follows, I describe how the relational self figured strongly in the interpretation of test results, feelings of guilt and/or relief, and disclosure of test results. In doing so, I attempt to describe the richness and diversity of what people care about and take responsibility for (Walker 1998).

**Concern for others**

While genetic information provided the foundation for guiding individual medical decisions, concern for others proved equally important in participants’ response to their test results. Genetic information crossed generational boundaries from the present to the future as
well as provided explanations for the past. Relationships with others, in particular family,
provided the matrix for interpreting the test results. Margaret, a mutation carrier, put it this way:

One of the things that needs to be said ... it was not my health problem. It now became a family problem. You know when you have cancer you just go and deal with it. It does affect people, but with genetic testing it becomes a whole family issue. It isn't just one person's issue anymore. It isn't just one person's health issue.

Parents, who had been previously affected by cancer, as well as those who were cancer-free, expressed particular concern about what their results meant for their children's health.

When I went in to get the results with [the genetic counsellor] it just happened that my daughter was with me. I was just going to run in and get the results and run back out and was even telling my daughter to wait in the car. But she said no, “I think we better go in momma.” She came in with me and [the genetic counsellor] opened up the letter and she told me that I was positive. MY FIRST THOUGHT was my daughter - that was my very first thought. I just started to cry and I thought, you know, I hope I haven't passed this on to my daughter or my son. (Unaffected mutation carrier)

Well my mom and my dad came along and my little boy. And there was little anxiety, like I was fine, I guess ...I was prepared to hear the worst you know. It was like I knew it was coming. And [genetic counsellor] just said what about your kids and stuff? That was my breakdown point (crying). Because you just, you know, you worry about your kids (Breast cancer patient, mutation carrier).

Indeed, a common theme among parents who had the mutation was guilt. Women who had already experienced breast cancer and tested positive for the BRCA1/2 mutation anguished that their daughters might share a similar fate. They, like those who were cancer-free, saw themselves as responsible for putting their descendants at risk and worried about the offspring’s health and future well-being.

It does evoke [guilt] because I'm the one that passed it on to them. So it does make you feel / like I wish I hadn't had it for my kids. That's what I was really hoping for, if I didn't have it then the kids weren't going to get it, right? But it didn't work like that (Unaffected mutation carrier).
The girls wanted to see how I made out and then it was their decision. I didn't pressure them. I thought well it's your decision if you want to know and be tested. So [my older daughter] got tested and naturally she had, well she already had the cancer too, and she had the same gene. [My younger daughter] didn't want to be tested until she found out if her sister had it... So then she was tested and she also had it. So it's a little hard for me (crying) (Breast/ovarian cancer patient, mutation carrier).

Others struggled with the thought that their children might hold this against them. Five of John's daughters inherited a BRCA1 mutation from him. Two have already been affected by early-onset breast cancer.

Well, they knew that the girls had breast cancer, but where it came from they didn't know until they checked my blood. And then they found out that I had the gene, which is unfortunate. It's a terrible thing for a father or a mother to pass a gene onto their children, but there's nothing that you can do about it.... I was sorry that I was the individual who had to pass it down to my children, but I can't help that... and I don't think that they are, but I only hope that my children aren't bitter because I happen to have it.

Catherine, a young mother who recently tested positive, expressed similar sentiments:

I can't let myself really dwell on the fact that [my daughter] would be the risk I am at. I hope there's better for her out there because that really concerns me and it concerns me how to bring her up.... Like I think when do I tell her that she could carry this risk? I worry what she might feel toward me, although at the same hand, I think that's silly because I don't hold any kind of grudge against my father. But I worry that she would be somehow upset with me if she does have the gene because it obviously comes through me.

She also worried about getting cancer and leaving her child motherless.

I worry too about dying and leaving [my daughter]. I know from my own experience just with my parents being divorced and being you know with one or the other parent how difficult that was, but they were alive so I really have a problem with the thought of leaving her. That just eats at me and motivates me to may be make choices I maybe wouldn't otherwise make. I don't know, but I really, it really bothers me with her.

As testing moved from the first generation to the second, some parents found themselves in the difficult position of knowing that they could or had passed the mutation

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102 Here, she is referring to prophylactic surgery.
onto one child and not another. This seemed to challenge their notions of parental fairness even though parents recognized who inherited the mutation was a chance event. Prior to his daughters being tested, for example, Bob had worried about how he would respond to this potential situation: "I can't explain how I would feel sitting talking to one that did and one that didn't. Especially being both girls." Conversely, although concerned about her daughter who inherited the mutation, Brenda was pleased the other one did not.

Hey, I'm glad one didn't [have it.] I was delighted for Carolyn. We were all happy for Carolyn. We weren't happy for Chris that she had it, but at least one of them, better than both of them having it, right? One of them got away with it. Like, my niece, she doesn't have it, and I mean that was delightful. My sister said, 'Oh, I don't know how to tell you this, but Terri doesn't have the gene.' I said, 'That's wonderful.' She said, 'Oh, I didn't want you to feel bad because Terri doesn't have it.' I'm delighted she doesn't have it, you know? I don't want any of them to have it. But one of them does, so...we just have to rally around Chris a bit more.

While parents frequently spoke of guilt about passing the mutation onto their children, daughters also expressed concern about the impact that their test results might have on their parents. For example, daughters from two different families acknowledged the difficulty of having to tell their mothers that they had inherited the mutation from them. Neither of these women was surprised to learn they carried the mutation that had passed through the maternal side of the family. Nonetheless, both were concerned that their findings would cause emotional pain for their mothers. In the words of one:

I kind of expected her [the genetic counselor] to say, yeah, I was positive just because of having it [cancer] so young, and being so much like my mother... But then, I just felt really sorry for my mom because she felt so guilty like it was her fault. You know, she's such a strong lady [but] you could see it in her eyes how hurt she was and that hurts me.

Kate, who came from a large family where testing has proceeded into the third generation, expressed similar concern about her father. In addition to her and her sisters, one of her nieces was found to carry a BRCA1 mutation. The mutation originated with her father.
Kate: I must say I do feel sorry for my dad and I hope, in some ways no one else gets tested. No one else gets tested positive. Because every time someone tests positive, I think it is hard on him...

L: It's been hard on him guilt-wise?

Kate: Yeah, sort of. Well, I think he understands it's not something that he could, you know, that he could control or anything. But every time someone else tested positive you could sort of see it in him... I don't know whether it's really a guilt, but a sadness, I guess. So with it really not affecting anyone else in the near future, I wouldn't be unhappy to see no one else be tested right now.

In addition to its health implications, parents frequently worried about the social consequences of passing the mutation onto their children. Many expressed concern that present and future offspring might face discrimination (employment, insurance, etc.) as a result of the family's mutation status. As Ross, a mutation carrier and father of three boys, stated:

On the down-side of things, genetic testing I think can be harmful in some ways for if on application forms now job interviews, application forms, I think they're / I have even heard that these there has been questions, have you a genetic disease? If you had testing? These types of things. I think if it was more readily known, I think it could hurt you in some ways may be. But that is the down-side of that.... Not for me but more for my boys. I would hate to think that it would go against them at any time.

Emphasizing the difficulty in keeping personal information confidential, Bill expressed similar sentiments about his daughters' futures. His wife was found to be a mutation carrier. She had both prophylactic mastectomy and oophorectomy in hopes of reducing her risk of getting breast cancer again.

Yeah, I worry about them. Like [my wife] has done everything she can do now. Now if that cancer comes back, [it] comes back, it's the luck of the draw. You deal you play the hand your dealt all the time....some people got good luck and other people don't and that's the long and short of it and you can't justify any of it. But I worry about the ramifications for my daughters, thank God. Like this world of electronics today, like the Internet and all this kind of crap, I mean they can catch dirt on every other living human being on earth. You know it just takes a push of a button to dig it out and that's what scares me is like this stuff has to stay private and I don't see how it can. I really don't. Like today, this day and age I mean there isn't a politician or a
movie star or anybody that can keep their life at all private. You're it's you in a fish bowl. If somebody's looking for you and if somebody decides OH YEAH well we want to hire people that are healthy or you know we don't want to give life insurance to people that might get sick or whatever you know like and I don't know what else comes with that, but there's probably other ramifications I haven't even thought of.

These and other examples help illustrate how genetic information is interpreted relationally, eliciting concern from parents about offspring and offspring about parents. As previously stated, it has implications about present, past and future generations in ways that other medical tests do not. Genetic information blurs the boundaries between self and other very quickly.

Up until now, I have only discussed the reactions of participants who received positive test results. Those who tested negative also considered their test results in relation to others. Just as parents experienced guilt in knowing they had passed the mutation onto their children, others were extremely relieved to know they had not or could not. As Barbara said, when talking about her response to her negative test result:

Probably the biggest thing for me, personally, is relief, because I don't have to worry about my children. They don't even have to give it a thought. I mean my daughter will grow up with your standard ten percent chance of getting breast cancer, right? And other than that, they don't have to think about it.

Carolyn expressed similar feelings about her unborn children:

When I found out I was negative I was relieved for myself, but I was more relieved for my non-existent daughters. Just 'cause I know that I won't have to worry about my daughters going through the same thing. 'Cause I can't pass it onto them. So it was kind of funny, 'cause I was relieved that I didn't have it, but I was also relieved that I can't pass it to my children.

This reaction did not pertain to parents alone. Martha, for example, described her relief in being able to inform her sister and mother that she had not inherited the mutation. Her sister and niece were already known carriers for Tay-Sachs disease. It was also suspected that her father had a form of inherited Alzheimer's disease. Her interest in undergoing testing
was overshadowed by a concern that she would be adding to the family’s genetic burden if she tested positive for the mutation. Nonetheless, because Martha had breast cancer at age 50 and was of Ashkenazi Jewish\textsuperscript{103} descent, she considered it her responsibility to undergo genetic testing for the sake of family. Her relief in learning she did not carry the mutation was tangible.

I had incredible relief. I felt as if a burden had been removed from me. I felt as if guilt had been removed from me because, yes, my aunt had breast cancer, yes, my mother had breast cancer. But it would be my fault in my head if I was telling her I was positive because I had initiated the process. I would be adding to the family burden.

As researchers have described with other genetic conditions (Codori and Brandt 1994), a few participants experienced survivor’s guilt; that is they felt guilty in testing negative for the mutation while other family members did not. Several times in our interview, for example, Carolyn spoke about her concern for her sister who tested positive. The relief in learning that she did not have the mutation was overshadowed by the fact that her sister did.

I think it would be different if we were both positive because I would be worried about my sister but at the same time I would be worried about myself. But now I don’t have to worry about myself, so I’m more worried about my sister. And I think I’m a lot more worried about my sister than I am worried about my mom, because I think that my mom can handle those things a lot better than my sister can.

I almost wish that it could have been the other way around because I think I was a lot more prepared to find out that I was positive than my sister was....I thought if anybody was going to get my mom’s genes, it would be me... It was the opposite than I thought it would be, but I guess something like that you can’t really predict. So I wasn’t disappointed and I wasn’t totally overjoyed. I wasn’t really, really happy that I was negative because my sister wasn’t. I was happy that I was negative but I was also really upset for my sister. ‘Cause now she has to go through it and I don’t want her to feel feel bitter towards me. I don’t think she feels it so much now but maybe when she goes through the surgery and as her life progresses and it becomes more, she’s more aware of it? Then I don’t want her to feel bitter towards me that she got stuck with it and I didn’t.

\textsuperscript{103} As stated in Chapter Two, three specific mutations have linked to Ashkenazi Jewish heritage.
Carolyn’s narrative provides a wonderful example of how the embodied self and relational self coexist at once. She was greatly relieved to learn that she did not carry the mutation (for both herself and her unborn children), but at the same time was worried about her sister who tested positive. Carolyn did not want her sister to feel bitter towards her because of this genetic imbalance. Genetic information brings to bear complex feelings about the self as well as the self in relation to other(s). Further, the interconnection between self and others is at the core of people’s moral identities.

In addition, some participants drew upon a notion of ‘genetic justice’ or ‘genetic fair play’ in thinking about who should get the mutation and who should not. Most often this was linked to who in the family had children. Jan, for example, experienced survivorship guilt in that she did not carry the mutation but her brother did. Her brother has two children, including a daughter who recently got married. Because she has no descendents, however, Jan felt that it would have been fairer for her to have the mutation than him. In her words:

I am going to see [my brother] in the fall so I am hopeful that we will have some conversations. My reaction, and my cousin said she had the same reaction, was a sense of guilt, the kind of survivor guilt, and especially because I don't have children. So really my concern is for my mental health, whereas he has a son and a daughter and his immediate concern was his daughter in particular. She just got married and would be thinking about having children at this stage. That's a serious legitimate concern and it seems it somebody, if one of us to have it, it would have been fairer for me to have it than him. So I said that to him, a little bit of that in my note and he didn't respond.

Jan recognizes that her feelings are “illogical” in that neither she nor her brother chose their genetic inheritance. Yet, she like many others, viewed her results in terms of its effect on others, in particular present and future descendents. In a similar way, Lorraine thought that it was more just that she had the mutation than her siblings. “In our family I think it's probably better that it was me who was positive because I have no children, so I'm not passing it on.”
Fairness, for both these women, seemed to be interpreted in terms of children, the next and future generations to come.

These examples illustrate that people integrate aspects of their life, with the lives of others, in making sense of their test results. Genetic information has import for oneself and one’s future health, but also is given meaning in relation to specific others. Moreover, participation in genetic testing may bring about new understandings of family. Sara, for example, learned about genetic testing purely by chance. She had no knowledge of her family’s cancer history until a distant paternal aunt told her mother about the BCCA’s Hereditary Cancer Program and extended an invitation to Sara to participate in testing. (Recall from Chapter 5 that Sara’s parents divorced when Sara was quite young. She moved with her mother to the lower Mainland, loosing all contact with her father’s side of the family). When she attended genetic counselling, the genetic counsellor showed her an elaborate family pedigree previously mapped out by her father’s relatives.104 In doing so, Sara learned about both her family’s cancer history and relatives she never knew existed. Her understanding of hereditary risk was made more confusing by the lack of communication with family members and uncertainty about her past.

It was just overwhelming for me, to sort of realize that hey, there are all these people that I am related to. All of the sudden there is this realization that something’s happening in the family and it could have affected me or could affect me. And I didn’t have a clue about it.... I don’t know if you feel bad or whatever, you just sort of feel like oh gee, what else did you miss?

While not representative of other participants, Sara’s story is instructive in that it highlights how genetic testing has the potential to challenge individuals’ orientations to family. The meanings people construct and what they do with genetic information rests on particular

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104 This practice raises questions about confidentiality of information, but it is beyond the scope of the thesis to pursue them.
assumptions about family members and relationships that precede them. Yet, it appears that genetic testing (coupled with pedigree analysis) may lead to new understanding of kin relationships and social relationships. Although I suspect there are relatively few families like Sara’s, this phenomenon may become more common with the increase of genetic tests for multi-factorial conditions.

Disclosure of genetic information

In addition to shaping responses, the relational self figured prominently in participants’ decisions to disseminate test results. As in any genetic test, testing of one family member for BRCA1 or 2 automatically provided information about the risk status of other family members and as described in the previous chapter, some people underwent testing for this reason alone. With only one exception, participants took it as their responsibility to inform other family members if a mutation was found. Many expressed the view that their relatives had a right to know, especially immediate family and female relatives within the current and next generation. Sandra’s comments are typical in this regard.

I think people have a right to know... if, for example, they hadn’t known and then they found it [cancer] later, I think they would be more angry, that well why didn’t you tell me about this? Especially if someone close to me dies. Well, why didn’t I? You know, you basically could have saved a life.

Similarly, Brenda who tested positive for the BRCA1 mutation did not hesitate to share her results with her immediate as well as extended family. When I asked Brenda whether there was anybody she would rather not tell, she responded:

This is a reality of life: don’t pretend it doesn’t exist. It does exist...[So is there] anybody I didn’t want to tell about it? Nobody. I’d tell the world. Doesn’t bother me at all that way. I think that it shouldn’t be such a scary thing to everybody. It’s not a fun thing, but it’s not really scary. It’s information. And we shouldn’t ever balk at information, even if it’s not great information.
While all participants told at least one biological relative about their genetic test results, the extent of disclosure varied with families. Some kept it to near relatives (parents, siblings, children), while others went to considerable lengths to inform more distant family (cousins, aunts, uncles) of their genetic test results. Two participants --both women-- sent out letters to every known member of their kinship. They thought it important that all family members be aware that a mutation had been identified in the family and that genetic testing was available to them. For a number of participants, this took on ethical significance. They believed they not only had a responsibility towards other family members, but an obligation and duty to share this information. Indeed, Sara talked about tracing a half-sister, whom she had never met, because of testing positive for the BRCA1 mutation.

That is one reason I would actually like to maybe get in touch with my half-sister. If only to say, hey, you know this is something that can be passed down through your natural biological father, and if you are interested at all, in being [tested]... I feel like it is important that maybe she be aware of it because she is my age and then again it is totally up to her. So I think in the next little while I am going to try getting a hold of her. I mean try finding her. I know she was put up for adoption, so I don’t know how hard that is going to be to her track her down.

It is important to note that this is not the first time Sara has thought about looking for her half-sister. At the time of the interview, her father had been quite ill, and she thought they might value the opportunity to meet each other before he dies. Sara’s knowledge of being a BRCA1 mutation carrier, however, has made the situation more urgent.

Most participants, however, did not feel an obligation to inform family whom they did not know. A few relied on certain family members to act as the liaison for more distant but known family. In each of these cases, women took on the primary role in communicating and exchanging information about the genetic risk for breast/ovarian cancer within the family. As previously mentioned, male participants also expressed a sense of responsibility to
be tested for their offspring. However, their communication of test results was restricted to spouses, children, siblings, and in a few cases, close relatives and physicians. It was certain female members within their families who then disseminated the information to the broader kinship and encouraged others to get testing as well. Thus, gender is significant in this study in that women tended to assume primary responsibility for this widespread familial communication.105

Gail’s story helps illustrate this pattern. Her husband had lost his mother and numerous relatives to breast cancer and she herself had helped nurse one of his sisters through the terminal phases of her cancer. As a key support to her husband’s family, Gail accompanied his sister’s daughter to genetic counselling and testing. When this niece was found to carry a BRCA1 mutation, Gail encouraged her husband and another one of his sisters to undergo testing. Her husband was found to have not inherited the mutation, while his sister did. Although pleased that her own children do not have to worry about genetic risk, Gail has taken it upon herself to disseminate information about genetic testing to the broader family network.

We’re reaching out and we will this summer definitely get in touch with them [cousins] and talk to them some more because there’s the two brothers and the two sisters - they must be in their late forties, early fifties- and they also have children...[My husband’s] one nephew, up in Alberta, I will write him a letter. I don’t know whether he’ll do anything about it, but I think he should know.

Moreover, it is important to note that many female participants did not limit communication of their test results to family alone. Emphasizing the benefit of genetic testing, the vast majority of women shared this information with friends, colleagues at work as well as others outside their family. Vicky, for example, wrote an article about her

105 These findings are also supported by Tercyak et al (2002), in an article on parental communication of BRCA1/2 test results to their children, they reported that mothers were significantly more likely than fathers to disclose information about their mutation status to children.
experience with testing and published it in her local newspaper. Margaret who lives in a
small rural community talked at length to local practitioners (both physicians and social
workers) about her test results in an attempt to “educate” them about the genetic testing
program. Veronica, who lives in a more urban centre, did the same thing. Leslie spent
considerable time with the mother of a good friend, explaining how she had used results from
genetic testing to gain control over her life. (Like Vicky, Margaret and Veronica, Leslie was
found to be a mutation carrier). Conversely, Martha took great pleasure in sharing her
negative results with members of her breast cancer support group. Because she did not carry
the mutation, this was seen as good news and rejoiced within the group. Although the small
number of male participants in this study does not permit a definite conclusion, men did not
appear to show similar patterns of communication. None of the five male participants said
they shared the news of their test results with people other than close family or personal
physicians.

While most participants valued the opportunity to share results with others, for some
women, communication of genetic risk information created responsibilities that were difficult
to fulfill. Lorraine, for example, took her duty to inform very seriously and was troubled
when some of her relatives did not seem to want the information. She felt that she had failed
to convey the importance of genetic testing properly and blamed herself for their lack of
interest. This caused her considerable angst.

I still feel badly that I am not sure that all of my cousins had the same information to
make the same informed choice that I did. Or that my sister did, or my brother, or my
cousins that I am close to. I mean I saw them. I gave them the information, we sat
around and talked about it. So I think they had enough information to decide what
they wanted to do. I tend to worry that these other cousins don’t have the same
information.... I kind of feel like we’ve got the inside track, we’ve got access to the
test, we’ve got the information and not everybody else did.
Lorraine attributed her sense of responsibility in part to her profession. She is a public health nurse and specializes in sexually transmitted diseases. She maintained that genetic information is no different from any kind of medical information. If one’s test results have implications for others in the family, she believed that everyone should have the opportunity to know.

Barbara, like other participants, was also concerned about exactly when to disclose this information to children or younger family members. Barbara’s niece had come to live with her because of difficulties with her immediate family. This young woman’s mother (Barbara’s sister) had died of breast cancer and Barbara pondered over when would be the best time to tell her about the family mutation.

She’s a little bit special needs and so I’ve got that additional thing of not knowing when she would be ready. Because she’s quite socially immature I don’t have a clue when, when would be a good idea, good time to, you know, have her be aware of that kind of responsibility. She’s very, very passive. I mean she has a lot of health problems and she just sort of sits there while my sister-in-law takes her to the doctor. She’s not even sure what she’s going for. Or my mother would take her or my mother would get her prescriptions filled. And so I’m not sure what to do with the fact that really she should be tested. But she’s just turned eighteen, so I will probably not even suggest it for at least three or four years.

As the above passages illustrate, participants largely viewed genetic information as beneficial for themselves and other family members. With this came the moral responsibility to share their results with others. Laura was an exception, however, in that she deeply regretted her decision to tell her children about her positive test results. She said it was one thing to know that there was a history of cancer in the family and quite another to know that it was linked to a specific genetic defect. She felt that knowledge of a family mutation carried a weight that family history alone did not have.

It’s like a game of Russian Roulette: when is that gene going to kick in? ...It doesn’t allow my kids the stress-free life...because they already know it’s in the family.
Whereas I knew there was a lot of cancer in the family but I didn’t know it was genetic...now my kids are always conscious, always aware, but with a real fear over and above the cancer, you know. They [might be] carrying this gene that produces this stuff.

Laura’s comments point to an aspect of genetic testing that requires further research: that is disclosure of test information to adolescents, in particular, teenage daughters. Adolescents, just as adults, will have diverse responses to this kind of information. But it seems that for some, genetic testing may provoke considerable anxiety or create a sense of vulnerability. How adolescents deal with this information needs to be examined. After experiencing her mother’s cancer illness, and knowing there is a mutation in the family, Laura’s 17-year old daughter is frightened and checks herself compulsively. In her mother’s words:

I feel for [my daughter] because you know I hear her worry about cancer or lumps or “mom, what is this?”..[She’s] checking everything. So there’s a lot with her…it doesn’t surface all the time but ...when it comes out you can tell she’s frightened. And we feel responsible, like look, what have done to our kids, right? 106

The final aspect of communication is non-disclosure. As clear as participants were about whom they would tell, some also spoke about people that were intending not to inform. For the most part, non-disclosure pertained to employers or people who were not close friends and family. As Liz said: “I don’t think it should be out in the open to everyone. It’s no one’s concern as far as I am concerned. It’s family’s business you know.” Catherine, who lives in a

106While disclosure of genetic information to adolescents deserves further research, I also think we need to question whether genetic information (access to it, knowledge of it) changes how people already are. In other words, do people deal with this information differently from how they deal with other aspects of their lives? Are those who tend to be anxious about things (for example, the ‘worried well’) more anxious about what genetic knowledge implies? Similarly, I do not think that we can examine children’s reactions to genetic diagnosis in isolation from their parent’s reactions. Daughters may inherit not only a genetic predisposition to cancer, but their parent’s fear of cancer as well. We tend to think about heredity in genetic/biological terms, but I would argue that people inherit all sorts of things from their parents (i.e. patience, bad temper, a ‘sharp tongue,’ love for sports, love for books, hate, etc.). Indeed, Lewontin (1991) reports that the two social traits, which have the highest correlation between parents and children in North America, are religion and political party. Yet, as he states, “even the most biological determinist would not seriously argue that there is a gene for Episcopalianism or voting Social Credit” (p. 32)
small town, said that she did not want people talking about her or misinterpreting what the information meant. She explained it this way:

From my experience with small towns is if you told a few people who told a few more people and told a few more people by the time the story gets down the line it would have gone from everything to I have breast and ovarian cancer to I am going to die of it. I don't at this point want to educate the whole town on genetic links to cancer. I don't even feel like I would be the right person to do that and I don't want people to look at me differently or treat me differently... I want most people to not know about it and to just deal with us and treat us normally, so I chose just to tell a few select people who I feel can keep that in confidence and I think that's worked.

Catherine’s comments point to some of the social consequences of genetic determinism. Because people frequently view genetics as destiny, some participants feared being seen as a ‘defect’ or treated differently. The potentially stigmatized are created when the information is used to categorize people as different (Kenen 1994). In addition, as Radley and Billig (1996) have observed medical conditions are subject to moral judgment. “Illness places individuals in the position of having to account for themselves against the background of potential criticism and imputed shortcomings” (p. 226). Indeed, a few participants decidedly chose not to tell spouses or other family members for this very reason. As Veronica explained:

When I found out that I have the BRCA 1 gene - I didn't want to tell my husband right away. And I didn't tell him right away. I don't think I told him for a couple of weeks or more after I had been told because I was afraid of the response that I was going to get from him. I was afraid that he was going to think that I was, how do I say it, not acceptable goods or, second rate or, you know, contaminated or whatever and I was right.

Veronica had a prophylactic oophorectomy after receiving her positive results. Her husband did not support her decision to have the surgery, nor did he help during her recuperation period. Her marriage broke down soon after that. However, I would be hesitant to say that genetic testing per se created this situation. Rather, as Veronica said, it had been a loveless
marriage prior to her surgery. "[I was] sort of a possession that he had. I was just his cook and housekeeper you know." Veronica’s reluctance to disclose her test results to her husband and his reaction to her surgery fit into a family narrative that had already included an oppressive relationship.

In a similar way, Jennifer chose not to share knowledge of her positive test results with her siblings. She described her childhood as miserable. Her father was an alcoholic, and her mother and older siblings had abandoned her when she was 16. She felt under no obligation to disclose her results to them.

Jennifer: You have to understand Lori, these women, my two sisters, and my other two brothers I haven't spoken directly face to face to them in twenty years. We're not talking about people that I have had a falling out with since I have got this genetic information.

L: You never had a relationship with them to begin with?

Jennifer: Never, never.

Conversely, Jennifer has been very willing to share her results with close friends and acquaintances she knows through her son’s activities. She has created a new family for herself, the bonds of which are not biological.

I have told all of them [my closest friends] but there are some moms that I am very friendly with on my son’s soccer team… that I have told…. We’re acquaintances through soccer but we’re not friends per se, but I have discussed it with them only because they are very supportive and they want to know how I am doing and they always are asking, you know.

To summarize, these accounts illustrate that participants interpret their genetic test results in terms of their embodied selves and well as selves in relation to others. Most perceived genetic information as beneficial and believed they had a responsibility to make this information available to other kin. It is easy to view individuals as acting in isolation and genetic information as no different from other kinds of medical information. In practice,
genetic testing is seen as a family affair and sharing of information is extensive within this realm. Different family attitudes, patterns of communication and relationships, however, affect how this information is shared and experienced. The majority of families experienced greater closeness because of genetic testing and disclosure of results, although a few exceptions did occur.

The social self

Up until now, I have explored the impact of genetic testing on the embodied and relational self. I have touched on kinship relationships and suggested that genetic testing has the potential to change the way participants think about themselves in relation to their family. Now I turn to the question: can genetic testing affect a person’s sense of social self? Catherine hinted at this issue when she said she feared that people would look at her differently knowing that she carried a genetic mutation. Social identity derives from attributes and appraisals of self that others make and is constituted by various social attachments (Charmaz 1987; Barclay 2000). Here I specifically refer to social identities formed around such things as ethnicity and/or religious beliefs. My interview with Anna provides the context for my question.

Anna grew up in East Vancouver with parents of mixed faiths. Her father was Jewish and her mother, Anglican. Her Jewish relatives considered her father “the black sheep of the family.” Not only had he married a gentile, but he was also a communist, had organized a jeweler’s union and led a strike against his brother’s factory. Ultimately, however, the marriage ended in divorce. Anna spent a lot of time with her father’s family but felt alienated because of religion. Her relatives reminded her constantly that she was not Jewish – it was her mother’s background, not her father’s -- which determined her faith. Further, these
relatives judged her mother to be inadequate as a wife, a parent and a housekeeper. Despite their constant disapproval and feeling that she had to defend mother, Anna longed to belong.

I went to live with that part of the family in Toronto when I was 15. Things were bad at home, my parents were separating and they [her father’s family] had something to prove, which took me a long time to understand. They were going to prove you know how good people lived, not like my mother, who couldn’t even keep a clean home or make her husband happy or raise children properly. So there was a lot of family history there but what I was told was, “You are not Jewish, there is no such thing as half Jewish. You are just not Jewish.”

Anna was diagnosed with cancer at age 45. She was not surprised – both her maternal grandmother and mother had died from the disease – but she did not expect to have to deal with it so young. Although her cancer was small and had spread just to one lymph node, she chose the most aggressive treatments. She also learned about genetic testing through her oncologist. Her physician suspected, as Anna did, that a mutation might have been passed through the maternal side of the family. There was only one case of breast cancer in her father’s extended family and nobody really knew or spoke about this relative (a paternal aunt). Anna went through genetic counselling and initially declined testing. She said the information would not change her course of treatment, and thought that a positive mutation status would cause her to worry excessively. About a year later, however, one of her close friends was diagnosed with breast cancer. This same friend had a normal mammogram 12 months earlier. Her friend’s diagnosis (an invasive tumour with multiple lymph node involvement) terrified Anna. Seeing how rapidly invasive cancer could grow caused Anna to change her mind about genetic testing.

While she knew there was cancer in the family, Anna was somewhat surprised to learn that she carried a BRCA2 mutation. Far more shocking, however, was the news that the mutation she carried was specific to Ashkenazi Jewish ancestry. Curious about its origins,
she obtained a tissue block from her mother for DNA analysis. Her mother did not have the mutation. Her father, who was 95 years old, agreed to have his blood analyzed for his daughter’s benefit. He was found to be the carrier and had passed the mutation onto Anna.

This information forced Anna to reconsider her ethnic and cultural identity. She said that she grew up always wanting to be Jewish, but had been told repeatedly by her relatives on her father’s side that she could not belong. In the Jewish faith, one’s heritage was determined by one’s mother’s religion. Her mother’s formal religion was Anglican, yet here she was found to carry a distinctly Jewish mutation. Was she Jewish or not? Several times during our interview she spoke how her genetic test results caused her to question her social identity.

Isn’t it interesting that after all these years of being told I am not Jewish, I wind up with the Jewish gene. Doesn’t that make you wonder who’s Jewish and who’s not?

Everything around this being Jewish, it was like an exclusive club that I couldn’t be in, no matter what I did. I mean you can convert, it takes you years, 3 rabbis and board exams but you never really going to be Jewish, right. And I didn’t understand that this was aimed at my mom and at my dad for doing this ridiculous thing of marrying a gentile, right. So then don’t I show up with Ashkenazi Jewish genes? And where does that leave me? I am not Jewish but I have the Ashkenazi Jewish gene for breast cancer.

Indeed, the irony of the situation has not escaped her. She believes her new found genetic status has earned her a place, or membership of sorts, in her Jewish family. She has recently been baptized in the Anglican Church and feels comfortable with her chosen faith. Nonetheless, she views her ties to the Jewish community, and likewise Jewish relatives, as changed because of her genetic mutation. While there are no clear answers, it has caused both Anna and her Jewish family to re-evaluate her place.

I got this gene from my father. This is the Ashkenazi Jewish gene for breast cancer. So am I Jewish? I mean it is just such an interesting thing. And the family are all sort of having to go “hmmm, I wonder?”
Given my druthers I would have chosen to be raised in a Jewish family and be Jewish because I am very attracted to the faith and the ritual... I wasn’t raised anything. My parents were atheists. My mom had been Anglican, but there was always a big hole there. So, I guess, you know, it’s instead of, gee I wish I was Jewish, I have this feeling of gee I wish they’d accept me, I am one of them, whether they want me or not, you know. I said to them, “You guys say I am not Jewish, but God thinks otherwise. My genes say otherwise.” So it’s given me a place to feel that I am not Jewish by religion, I have chosen my faith, but by culture, by history, by ethnicity. I am content with that. It has kind of helped with that hole of not knowing who I was.

Although a single example, Anna’s narrative raises important questions about the impact that genetic testing might have on an individual’s sense of social self. By virtue of where, when and to whom we are born we inherit a social and cultural identity. As Elliott (2000) writes: “To be a Southerner, a Jew, a Quebecois, an Irishman, is to be born into a certain way of seeing and being in the world. This is part of what makes us who we are” (p. 9). What happens then when someone’s social identity is contested because of genetic information? What gives a person membership into a particular culture? The criteria used to define group identity are complex. Nonetheless, Anna’s story impels us to ask whether genetic information has the potential to affect orientation to a particular social or religious group. Can we assume that people belong to particular ethnicities or groups because they share a genetic characteristic? I suspect that most people would support the view that genetic identity does not automatically grant them affiliation within a community. As Davis (2000) writes: “It is easy to imagine someone with the genetic identity of an Ashkenazi Jew who has no ties to the group and shares few of its values or concern, while a person adopted into an Ashkenazi family at birth might exhibit robust membership in that community in every sense but the genetic” (p. 41). Indeed, group identity is shaped by many factors including values, purposes, interests, languages, religions, location, diet and so forth. Whether and how genetic information intersects with these entities remains to be seen. At the very least, as
Anna's story has shown us, it presents some interesting challenges that may cause individuals and families to rethink who they are or where they fit in.

**Age related concerns**

Thus far, I have shown how genetic information has implications for self-identity. I have described how genetic test results influence the way that individuals think about their physical well-being (embodied self), relationships and responsibilities to others (relational self) and their identity within a social community (social self). In this section, I take a somewhat different turn by exploring concerns raised by genetic test information in relation to age, or more specifically, stage in one’s life. As feminist scholars remind us, moral agency and self-identity are shaped by a multiplicity of factors including ethnicity, sexuality, religion, age, socioeconomic status, location and other socially marked differences (Meyers 1997; Mitchinson 1998; Sherwin 1998; Walker 1998). While I cannot examine all these factors in depth, a striking theme that emerged from my analysis is how genetic information poses different questions and choices for younger adult women than those who have had their children and/or are in their middle years. My findings need to be substantiated with greater numbers, but I hope that a brief examination will illustrate how life stage plays a significant role in shaping moral issues and choices raised by genetic testing. This approach contrasts with psychological surveys on genetic testing for breast/ovarian cancer, which frequently view age as a confounding variable or something that must be controlled for in order to examine the effects of genetic testing alone (Croyle, Smith et al. 1997). Yet, based on interviews with participants, I would argue that “controlling for age” conceals significant findings about the moral and social implications of genetic testing.
Young Adult Women

Of the 39 participants who underwent testing, nine were 20 to 35 years old. I do not view this age range as definitive in itself, but rather use it as a broad indicator of life stage (Waxier-Morrison, Mears et al. 2000). Most participants in this age range had come to know breast/ovarian cancer through empathetic experience; that is their life stories included living with someone with breast cancer and/or witnessing the death of close relatives. One woman learned about her family history by ‘accident’ and two by family stories told about relatives who had already died. All of these women were among the second generation in their families to undergo genetic testing (that is a mutation had already been identified in a parent and/or other relatives). Seven of the nine learned that they had inherited a BRCA1/2 mutation.

As Waxier-Morrison et al. (2000) assert, early adulthood suggests a particular kind of social context. Many women in early adulthood are concerned with the future, in particular establishing careers, relationships with friends, partnerships and possibly having children. In middle years, the context shifts to one that generally includes more stable living arrangements, employment, friendships, partnerships and child-rearing. At the same time, the threat of breast cancer is frequently more immediate for those in their middle years than in early adulthood. This is the age where it often occurs. Thus life context is quite different between these two broad stages. This, in turn, promises to affect how genetic information is interpreted and used.

Indeed, for most young adult women, genetic risk presented a future concern as opposed to something that had to be acted on immediately. Only one woman in this group elected to have prophylactic mastectomy; the remainder chose to engage in surveillance
programs. Younger women shared similar concerns to those in their middle years and talked about the impact of embodied risk in terms of an aware self, safe self and uncertain self. However, only younger adult women comprised those who viewed their selves as “risky”.\textsuperscript{107} Recall from the section on the ‘risky self’ these participants did not have much faith in screening measures (either breast self exam or mammography),\textsuperscript{108} nor did they consider prophylactic surgery an option because of their age, concerns about femininity/sexuality and future plans to have children. While I am hesitant to say that age alone is a predictive factor here, the long-term impact of genetic knowledge requires further examination. Is there a tendency for the lives of younger women to be more affected by the foreshadowing of disease suggested by genetic information?

Further, my interview with Reda shows that people’s perspectives about genetic testing can change over time. Recall from Chapter 6 that Reda first learned about genetic testing when she was 22. Her mother, who had breast cancer when Reda was an adolescent, and several of her aunts had already been found to be mutation carriers. When we first met, she had rejected testing for herself altogether. In a second interview a year later, she felt quite differently.

L: Last year when we talked, you weren’t really interested in genetic testing at all. Do you still feel the same?

Reda: No. Well, no, I don’t. I feel a little bit different about it now. Actually in my Biology 110 course I did a paper on genetic testing for breast cancer. I think it’s a little bit more scary now than before.

\textsuperscript{107} It is important to keep in mind that the interviews encompass participants’ responses at one point in time. For example, a number of women in their middle years stated they felt ‘safe’ once they had their surgeries; prior to that they were extremely concerned about their risk. Thus the interview reflects a time when they felt ‘safe,’ as opposed to when they were burdened with fear, which started in their early adult years.

\textsuperscript{108} Younger women’s concern about effective, screening tools is clearly warranted. The efficacy of mammography in younger women is known to be less because of the difficulty in imaging dense breast tissue. Also both clinical and breast self exams (even if done properly, which is frequently not the case) can easily miss the early, small cancers.
L: And why is that?

Reda: Because you're, you can foresee it coming.

L: It's a little bit closer to you, is it?

Reda: Yeah, yeah, a little bit closer. A little bit more severe. You know, I went from not caring to, to caring.

L: And did anything in particular bring that on?

Reda: No, I don't think so. Maybe my age. I see the seriousness of it, maybe.

This latter passage indicates how individuals' responses to genetic testing are not fixed or absolute. Just like one's values and sense of identity, they may shift over time. Genetic testing had no utility for Reda at age 22, but she saw it quite differently a year later. Thus, an important question to ask is what is the long-term impact of knowing this information? Because most young adult women do not view prophylactic surgery as an immediate option, do they become distressed about their embodied risk? Accordingly, how does long-term knowledge of a genetic risk affect notions of self, agency and capacity for intimacy and relationships with others? Although I am mindful that experiences around genetic testing are shaped by a host of factors, we need to examine more closely the potential for harm in young adults. Kelly's (age 28) remarks are poignant in this regard.

It [genetic testing] does bring a different light on those big issues that you have to deal with in life. The decisions that my mom and [my aunts] are making are decisions that are only going to affect basically their retirement. This affects the rest of my life. I mean my sister, she's six years behind me. She hasn't even got into a serious relationship let alone decided where her life's going to go.

As the above quote indicates, the choices rendered by genetic test information can be quite different for younger adult women than those in their middle years. It also illustrates that the self in relation to others is integral to younger women's interpretation of genetic
testing. Indeed, looking to the future, all participants who fell in this age range talked about the reproductive implications of genetic information on having children. Genetic knowledge caused them to re-examine their responsibilities, choices and future identity as mothers. In doing so, three main concerns came to the fore: (1) Do you have children, knowing that you might pass the mutation onto them? (2) Do you have children knowing that you are at high risk for cancer and may not be able to care for them at some point in your life? (3) When should you have children?

Indeed, having received their test results, younger adult women faced different reproductive decisions than their parents. Although the latter knew that cancer ran in the family, these young women had definitive knowledge of their carrier status. With few exceptions, younger adults who tested positive queried whether they should have children knowing that there was a 50% chance they could pass this mutation onto them. Marilyn, age 29, described her feelings about it this way.

I and [my sister] always joke because if you look at our family, well who had the gene that didn't get the disease? No one. Well, you know excluding men, but women they all had it, they all got it. And sure you can look at the bright side and say well some of them didn't get it until they were in their seventies, but you know they did get it. So it seems you know seems like in our family, it's running more like a hundred percent, so that's scary. So then you wonder about having kids and stuff like that as well...and passing it on. It's hard to make those decisions about what the best thing is to do.

Kelly, who was 27 at the time of our first interview, expressed similar concerns prior to receiving her test results.

And there have been issues in my own life that I've been trying to deal with. I mean the biggest issue of this was having children for me, and it's been something if I am genetically positive that may influence my decision of having children. I always thought that I would have children and if I'm genetically positive I don't know if I will

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109 The effect of genetic knowledge on reproductive behavior has been observed for other hereditary conditions. Examples include Downing (2001), Parsons & Atkinson (1992) and Lippman-Hand & Fraser (1979).
or not. Not in that would be the total deciding factor, because of course there is umpteen million factors to having children, but it's a [factor].

Concerns about having children, however, were often countered by participants' reflections about their own lives. A tension existed between the appreciation of one's life and concern for passing this mutation onto future offspring. As Marilyn implies in the following passage, she would not have wanted her parents to have done anything differently based on this information alone.

But then I have to think well gee if my dad would have known, you know my mom and dad would have known, would I not want to be here kind of thing? Would I say oh they shouldn't have had me if they knew and you know I wouldn't be here right now. Like that's one way to look at it. Would your kids ever regret being born because you knew? I don't think they would. If they did they probably have other problems you know that they may be don't want to be here, but it's not necessarily because of the gene.

Catherine held a similar perspective. She was already pregnant with her first child when her father told her that he carried a BRCA1 mutation. She underwent testing and learned shortly after the birth of her first child that she had inherited the mutation as well. When I met her, she was pregnant with her second child.

We definitely were planning to have children and I was pregnant when we found out about the possibility of being tested so that I know that the question of should or shouldn't we have children it was already answered for us. And I'm glad in that sense that it was [because] it made it really easy. I was already expecting her. And I guess I don't want to deny her a sibling or siblings because of this and I am optimistic that things will hopefully improve for and her sibling... although it is/ it does pose an interesting question like should or shouldn't you have children? But I guess if my parents had have known that you know twenty-seven years ago or twenty-nine in the case of my sister like, so they would have chosen not to have us? I mean like I don't want to think that that would have been the case you know. Like I'm glad to be here. I don't look at it and think Oh, I should have never been born you know, so I hope that [my daughter] will look at it like that too. But it is an interesting dilemma ....about having children you know because you have that risk of passing it on.

Concern about having children was not restricted to passing on the mutation alone. Younger adult women also expressed a duty or responsibility to protect their potential children from
watching them suffer from a painful illness. Many had witnessed their mothers or close relatives struggling with the disease and did not want their children to live through what they did. As Kelly said:

I know how it affected [my aunt’s] children to see her sick and I guess in a way [with my mother] how it affected me too. And I think I don't want my kids to go through that...say I had kids tomorrow, I am going to be at the prime age in ten, twelve years so then they’re ten, twelve years old and to see their mother sick like that. I don't know if I would want to do that.

Other participants spoke about their ability to fulfill their parenting roles. Do you have children knowing that that you are at high risk for cancer and may not be able to care for their children once they are born? As Marilyn put it: “I had a problem right off the bat with having kids because number one, I didn't want to pass the gene on to them; and number two, I didn't want them to be, you know, five and three and have me die.” These responses once again highlight concerns that arise out of a relational self, in particular, a self that is influenced by responsibility for others in their lives.¹¹⁰

As younger adult women worked through these issues, however, most came to the decision that their mutation status alone would not affect the decision to have children.¹¹¹ They put their faith in science and held out hope that something better than prophylactic surgery would be available to their future daughters. In Catherine’s words: “I am optimistic that things will hopefully improve [my daughter] and her sibling.” Kelly expressed similar sentiments.

¹¹⁰ The response was also expressed by a participant who declined testing, but had breast cancer in her mid-thirties. She wished to have children, but worried about the possibility of recurrence and what that meant to her long-term survival and ability to parent. She did not want her children to see her sick or die.

¹¹¹ Of the nine participants, I perceived Marilyn to voice the strongest hesitancy about having children because of her mutation status. However, I met her aunt (whom I had also interviewed) at an educational workshop on genetic testing three years after this interview. In catching up on each others news, she told me that Marilyn had a child and was expecting a second very soon. This implied to me that over time, Marilyn saw her mutation status as no longer an impediment to having children.
So we talked about it again and we sort of reexamined it, and [my partner] said to me, ‘You know what? I’ve been thinking about it and he said it doesn't matter to me. And I said, well, you know, it still bothers me a little, but I think having kids is more important than that and I can only hope that technology moves along and something can be done for this, for our child.’ And actually today I found out that I'm pregnant.

Thus, while it prompted considerable soul-searching, mutation status ultimately did not pose an impediment to child-bearing for the young adult women in this study.112

Interestingly, however, participants talked about knowledge of their mutation as affecting the timing of when they would have children. Concerns about their own health, the perceived need for future prophylactic surgery, and responsibility to parent once they had children, spurred a number of young adult women to think about having their children sooner than later. As Alice (age 33) put it:

I don't have kids right now. I wouldn't be so worried about passing the gene on because I think by the time that they were twenty or, you know, thirty it would be that much more advanced. So that doesn't really concern me as much as, you know, if I do decide to have the surgeries. That would mean that, you know, we better get it now and have kids right away sort of thing.

Genetic information clearly served as the catalyst for Kelly to have her children at a younger age. She learned that she carried the mutation when she was 28 years old.

We [my partner and I] sat down and we had another conversation about it because basically the reason being is we didn’t want me, us, like if we were going to have kids, we didn’t want to wait so long to the point where I was in the real high risk group and didn’t have the option of surgery because we’re waiting to have kids.

We had some things going on in our life and we said once all of this is done, we’ll sit down and we’ll talk about it and we decided that it was time to start trying. So that I wasn’t in my mid-thirties and starting to think, should I be thinking about surgery, and then you feel like you’re under the gun. Although I think we rushed it a little, we were both ready, but I think we maybe pushed ourselves to be ready faster than if we didn’t have this hanging over our heads.

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112 The small numbers in the study preclude me from making a generalization here. Also, I am not convinced this observation will hold for everyone. For example, in speaking about their daughters, two mothers told me they were sure their daughters would not have children if found to be mutation carriers. These women had an extensive (and brutal) history of breast/ovarian cancer.
Findings also suggest that 'not' having the mutation is equally important to considerations for the future. The two participants who tested negative spoke about the impact of this information on child-bearing as well.

It impacted my life just because if I would have found out that I was positive I might have had kids a little bit sooner, but now I'm putting it off until I'm financially stable (Participant, age 23).

If I one day wanted to have surgery, I would want to do it after I had children... but the timing was, you know, I was thinking... we were trying to have children and this could be something in my life, this gene, so maybe we need to get a move on with kids. But not having the gene, we could relax a little a bit with the plan. I mean we still kept trying, but it wasn't quite as critical (Participant, age 33).

While this section focuses on the responses of young adult women, I think that it is important to point out that some mothers also advised their young adult daughters to consider having their children at a younger age. As Anna said:

My discussions with [my daughter] went on for quite some time and I said to her there is absolutely no reason for you to be tested now. The only thing is, you might, you know, if you find the right partner, you might decide to have your kids young and then look at it and, you know, get parts removed.

I suspect that parental advice and what other family members do will also influence the decisions young adult women make.

Leslie (age 34) chose another option still. Because of her family history of breast and ovarian cancer, as well as personal experience with fibrocystic disease, she decided to have a prophylactic mastectomy soon after learning she carried a BRCA1 mutation. At the time of our interview, she also planned to have prophylactic oophorectomy in the near future. While Leslie did not plan to have children, she thought of another way to retain this option in case she changed her mind.

Leslie: [I] don't really intend to have kids, but I'm going have them frozen/ I'm going to have my / fertilized and frozen.
L: You're going to have your eggs frozen? Is that what you're saying?

Leslie: Yeah, in a couple of years. I'll have my eggs harvested and fertilized and frozen, so if I ever decide -- I don't really think I will -- but if I decide to I can have those [children] too.

Leslie’s comments are instructive in that they remind us people are very creative in responding to health challenges. Young adult women, just as those in their middle and later years, do not passively accept genetic information but negotiate it within the context of their everyday lives. Yet it appears that different moral questions and choices are associated with life stage. As just described, child-bearing is a focus of concern for many younger adult women. Some decided to have children at a younger age than they might otherwise with the intent of have prophylactic surgery afterward. Leslie opted to harvest and fertilize her eggs so that she could have an oophorectomy and children as well. Obviously, for women in their middle years, reproductive decisions are not likely to be as great a concern. At the same time, because of their age, the physical threat of cancer is more pressing for this group. Because women do not distinguish health concerns from other matters in their lives, agency and self-identity will be affected in different ways.

Summary

This chapter presents my construction of how genetic test results (both positive and negative) are understood. Two fundamentally philosophical questions shaped the analysis: Does genetic knowledge change the way we think about ourselves? Does it expand or restrict the control that we have in our lives?

I used three categories of self – embodied, relational and social\textsuperscript{113} to explore these questions further. For the most part, participants linked their positive results to becoming

\textsuperscript{113} To reiterate, I make these distinctions for heuristic purposes only. All three aspects of self are connected to a person’s identity, that is her sense of who she is.
more aware of their embodied selves. They said it allowed them to enact measures that would increase their physical safety (i.e. surveillance or prophylactic surgery) or gain access to services they were previously denied. These women considered genetic risk as something to be dealt with, managed and possibly overcome. The quality and depth of their lives improved after they had taken measures (most often prophylactic surgery) to confront the disease. However, for a small minority of women knowledge of genetic risk had a profound and limiting effect on their agency. Rather than giving them a sense control, they saw little opportunity to fight the disease. They were overcome by thoughts of their embodied risk and a dire future from which they could not escape. And others still were thrust into a state of uncertainty. These participants did not view themselves as risk-free, yet neither did they perceive themselves as unhealthy. While worrisome at times, knowledge of their mutation status became part of their awareness, part of their routine lives and ultimately (as in the previous groups) part of who they were.

The self in relation to others proved equally important in participants' interpretation and responses to their test results. Many individuals in this study viewed genetic testing as a way to 'do right' by their families. It allowed them to obtain what they perceived to be valuable health information for themselves and others. Yet, through genetic testing, the past and the future became part of the present creating relational concerns that spanned generations. Positive results elicited concern from parents about present and future offspring and offspring about parents. Those who tested negative spoke of relief, as well as guilt in that they were spared the mutation when other family members were not. For some, this led to notions of 'genetic justice' based on who had descendents and who had not. One participant worried that she had done 'harm' to her children by proceeding with testing. A positive
mutation appeared to mark a crossing from a possible risk to an actual threat. For some, knowledge of a family mutation provoked considerable anxiety and created a sense of vulnerability that history alone did not.

The findings also emphasized the importance of responsibility in participants' responses to genetic information. For the most part, participants viewed genetic information as information about the family and thus felt a responsibility to make this information available to kin. Both women and men expressed a willingness to share their genetic test results within their biological kinship. However, women were more likely than men to share information outside the nuclear family with extended family, friends and others members of the community. Moreover, many female participants did not limit communication of their test results to family alone. Emphasizing the benefit of genetic testing, the vast majority of women shared this information with friends, colleagues at work as well as others outside their family. While we need to be wary of the gendering of responsibility, it is through responsibilities to others, as Walker (1998) writes, we define ourselves as moral beings. At the same time, it is important to remember that the responsibility engendered by genetic testing can affect women and men’s lives in both positive and negative ways. In addition to who, disclosure raises the dilemma of when and how to tell.

Beyond the scope of this dissertation, however, is an exploration of the consequences of such disclosure – specifically do people welcome getting medical information, which they have not sought themselves? How does this affect family relationships or self-identity within a particular family? The interviews with Sara and Anna indicate that genetic information can bring about new understandings of kinship as well as personal and social identity. Further empirical research is needed here on how genetic information is received by adolescents.
Recall that one mother greatly regretted her decision to tell her adolescent daughter because of the anxiety it caused her. Family history, coupled with less stability, may make this age group particularly vulnerable to the information and affect their understandings of present and future self.

People’s responses to genetic information will be shaped by a variety of factors including socio-economic status, ethnicity, age and geographic location. Indeed, an examination of ‘life stage’ shows how genetic information raises different moral questions for young adult women. In particular, reproductive decision-making is made more complex. Ultimately, young adult women in this study did not view a positive BRCA 1/2 finding in itself a reason to forego having children. Yet, it certainly prompted them to consider when was the ‘best time’ to have children. Young adult women who intended to have children balanced family planning with decisions to have prophylactic surgery. Unlike other hereditary conditions for which there is no cure, prophylactic surgery promised some opportunity for control.

In closing, genetic testing illustrates the nexus between the individual and collective identity. By observing how people respond to genetic information, we gain insight into the interconnectedness between the individual, relational and social self. Although I have strong concerns about some of the consequences of genetic testing (i.e. breast reconstruction and/or oophorectomy with no clear medical guidelines regarding hormone replacements) participants taught me that it is extremely difficult to deal with uncertainty, especially when one’s life may be at stake. Thus, a course of action that seems harsh, drastic, unreasonable and even mutilating for those who do not live with hereditary risk makes practical sense for those who do. In listening to how participants interpret this information, I learned that we
need to look at agency and decision-making within the everyday experiences that shapes people's decisions. Carolyn's comments are particularly relevant here.

It's funny 'cause I talk to my friends sometimes and I explain to them the surgery that my mom went through, and they said, 'Oh, so your mom had breast cancer.' Like, no, she didn't. They never actually found breast cancer but she was at high risk and lots of my friends can't understand why she would go through the surgery if she didn't have breast cancer. But I think if they would have seen everything that our family went through when we were growing up, then they would feel a lot differently about it.
CHAPTER 8

Attending to Broader Social Discourses

Geordie was puzzled at first by the direction of her questions. He was so used to telling people about the trenches—that’s what they always wanted to hear -- that it took him a while to understand that Helen was interested in the ways in which over the years, he’s learned to manage his memories. Once he understood, he was interested in her theories, though he always denied that his memories had changed to accommodate changes in public attitudes to the war. ‘I wish they did change,’ he said, trying to get her to see the perpetual present in which his worst memories existed...The wordless, hallucinatory filmic quality of his memories. A flare goes up, illuminating bleached sandbags and tangled wire, but the trembling light never fails. A scream begins and never ends. For Helen, memories are infinitely malleable, but not for Geordie. Geordie’s past isn’t over. It isn’t even the past.

---Pat Barker, Another World

Introduction

The preceding quote reminds me how theory shapes the research questions we ask, what we attend to, as well as what we hear and see. Feminist epistemology, for example, directs attention to the particularity of knowledge as well the structural forces which organize this knowledge. It invites us to consider how social, cultural and political factors shape what we know and whom is thought to know. Matters of epistemology, like those of ethics, involve issues of power. In the words of Walker (1998): “Some people, more than others, are assumed to know, or know how” (p. 57). Likewise, some people more than others are assumed to know (and can dictate) what is right.

While our theories serves an important purpose, I sometimes worry they can impede our ability to listen. In other words, would our participants agree with the theoretical lens we have chosen to frame or describe their experiences? Listening, just like seeing, is not an objective activity. We hear/see with our minds as well as our senses and thus may perpetuate unconscious biases, misconceptions and paradigms produced by the training that teaches us
to see/hear things in certain ways (Goldstein and Goldstein 1978). When considering the representations we have used or that the academy permits, we need to constantly ask ourselves: What community do these representations claim to represent and whom do they actually represent (Walker, 1998)? Do claims of knowledge refer solely to those whose expertise is validated in hierarchical systems? Fiction author Pat Barker captures this point when writing about Geordie, a soldier in World War II, “For Helen [a sociologist], memories are infinitely malleable, but not for Geordie. Geordie’s past isn’t over. It isn’t even the past.” With this quandary in mind, I now proceed to consider how different ideologies and discourses intersect with participants’ experiences of genetic testing.

One of the goals of critical ethnography is to make visible how larger structures and processes influence and shape individual experiences (Britzman 1991; Denzin 1997). The preceding chapters have highlighted the complex and multi-dimensional experience of familial cancer and genetic information on understandings of the embodied, relational and social self. Although I am concerned about the everyday impact of genetic testing, it is important to situate participants’ accounts in a broader context of dominant discourses about genetic testing and cancer. In this chapter, I discuss three ideological themes that underpinned many of the comments made by participants: the ideology of genetic determinism, the ideology of breast cancer survivorship/fatality and the ideology of choice. I then link these themes to some of the central ideas presented in the preceding chapters: relational selves and experiential knowledge; relational selves and moral/social identity; relational selves and responsibility. I wish to emphasize, however, that while I present these ideological discourses and themes separately, they are not distinct but intricately entwined.
Before I begin, however, a preliminary note about terminology might be helpful. As Mills (1997) points out, the term ‘discourse’ has gained wide popularity in a variety of academic disciplines ranging from critical theory, linguistics, sociology and anthropology to philosophy (pg. 1). Its general usage, however, has led to some confusion about the meaning of the term. Here, I take as my starting point a definition of discourse offered by Mills (1997): “A discourse is something which produces something else (an utterance, a concept, an effect) rather than something which exists in and of itself and which can be analyzed in isolation. A discursive structure can be detected because of the systemacity of the ideas, opinion, concepts, ways of thinking and behaving which are formed within a particular context and because of the effects of those ways of thinking and behaving” (p. 17).

Discourse, through language and text, reflects beliefs, values, attitudes, as well as commonly held assumptions and ideologies and resistance to those ideologies. Thus, discourse structures both our sense of reality and how we see ourselves in the world (Mills 1997). My intent here is not to conduct a discourse analysis, but rather to examine how certain ideological discourses about genetic testing and breast cancer may inform or conflict with people’s life experiences.

The ideology of genetic determinism

Geneticization and genetic determinism have become a pervasive part of critiques aimed at genetic testing. Abby Lippman first coined the term geneticization in 1991 to describe the tendency of medicine to distinguish people, behavior and illnesses on the basis of genetics. She writes: “Geneticization refers to an ongoing process by which differences between individuals are reduced to their DNA codes, with most disorders, behaviors and physiological variations defined, at least in part, as genetic in origin” (p. 18-19). It is an
attitude that incorrectly equates human biology with human genetics, implying that "the latter acts alone to make us each the organism she or he is." More recently, Lippman (1998) has described geneticization as both an emerging ideology and a set of practices. As an ideology, genetics comprises a host of social, philosophical and political understandings, which promote the notion that heredity predestines our lives. Indeed, the fact that genetics has been so willingly embraced by society at large suggests that genetic knowledge shares much with our pool of common knowledge. Like any paradigm that readily takes hold, there must be some coherence "some perceived truth" between the way scientists see and the way the public sees (Kuhn 1970). As a practice, genetic technologies are increasingly being applied to diagnose and categorize (and eventually treat) conditions previously identified and managed in other ways. They may also lead to the creation of a whole new set of disorders through constructed notions of genetic risk (Lippman 1991; Lippman 1998).

Asch and Geller (1996) point out that as a scientific discipline, genetics draws on dominant individualist and reductionist traditions of western biomedicine. The biomedical model conceptualizes the individual as the proper subject of health and target for health care interventions. The commitment to a reductionist view of the body is influenced by assertions regarding biology's hierarchical order (Good 1994; Morgan 1998). Here, disease is viewed as resident in the individual body, and "the goal of treatment is to understand surface phenomenon with reference to a deeper ontological order, to link symptoms and signs to physiological structure or functioning and to intervene at that level" (Good, 1994:83). The discourse on genetics is a further extension of this reductionist approach. Using the metaphor of blueprints, with genes presented as master molecules and DNA fragments as a set of instructions, it reduces health problems to the individual and situates individuals increasingly
according to the pattern of their cells, molecules and genes (Lippman, 1998; 1991). It encourages us to look at illness (and health) as genetic in origin and to view genes as deterministic. Disorders thought to be genetic, for example, may be seen as unavoidable or inevitable, in fact that our genes are our destiny. The ideas embodied in the ideology of genetic determinism are not new but tap into a commonly held view that our genetic make-up is “more fundamental and more unalterable than any other variable in the equation of life,” (Surbone 2000: 51).

Finkler (2000) captures much of this in describing how prevailing notions about genetic determinism may convert women into potential patients. Women who have inherited a BRCA mutation, for example, may be categorized as those who are not yet sick but not quite healthy. Rigorous screening programs, twice yearly clinical check-ups, breast self exams, transvaginal ultrasound and so forth may make women view their bodies as diseased, even though it may be years before (or if ever) the disease appears. She claims that genetic risk is two faced: it deprives people of their “agency” (in that we are the product of our genes), yet it gives people (rightly or wrongly) a sense of control by promoting the view that there is something they can do about it. “ It permits modern humans to nurture the notion that they can control the future by controlling risks.” (Finkler 2000:7). She, like many other critics, also argues that geneticization may re-ignite tendencies to characterize people as other, to further marginalize groups already disadvantaged on the basis of supposed racial or ethnic heritage (Keller 1992; Nelkin and Lindee 1995; Asch and Geller 1996; Sherwin and Simpson 1999; Davis 2000). On a societal level, critics fear that geneticization will promote a return to eugenics and disregard of the social and environmental determinants of health. On the level of the individual, they caution it will result in increasing medicalization of people’s
lives (Lippman 1991; Lippman 1998; Lock 1998; Sherwin and Simpson 1999). Like other medical technologies, genetic testing threatens to undermine women and men's autonomy by putting them under the control of experts (Morgan 1998).

Critics' reactions to genetic testing are not without warrant. Biologists have frequently overstated the link between genetics and biological function. Richard Dawkins (1976), for example, advocated an extreme view of genetic reductionism in which he described human beings as "survival machines—robot vehicles that are blindly programmed to preserve the selfish molecules known as genes" (p. 24). The Human Genome Project\footnote{Recall that the Human Genome project is an international collaborative effort designed to sequence and produce a detailed genetic map of the DNA within a human cell. This three billion dollar project began in 1990 with the expected completion date of early 2003 (Wood-Harper and Harris, 1996).} proceeded on the assumption that gene sequencing would reveal all that was necessary for understanding of biological function (Keller 2000). Indeed, referring to the HGP's potential to disclose the secrets of our genetic makeup, the Nobel Laureate Walter Gilbert wrote (1992): "Three billion bases of sequences can be put on a single compact disc, and one will be able to pull a CD out of one's pocket and say, 'Here is a human being; it's me'" (pg. 96). The search for the genetic basis to human behaviors, such as alcoholism, depressive/schizophrenic illness, shyness, fearfulness and violence, continues even today (Kevles and Hood 1992). Other scientists, however, counter that this account of genetics is over-simplified and misleading (Lewontin 1991; Gould 1992; Hubbard and Wald 1993; Lewontin 2000). In Biology as Ideology, Richard Lewontin asserts that development depends not only on genes inherited from parents, but on the environment (both physical and cultural) in which the organism is found. Moreover, these are not independent pathways. He writes:

> Genes affect how sensitive one is to environment, and environment affects how relevant one's genetic differences may be. The interaction between them is indissoluble, and we can separate genetic and environmental effects statistically only
in a particular population of organisms at a particular moment with a particular set of
specified environments. When an environment changes, all bets are off (1991: 30).

He and others also assert that as an ideology genetic determinism fails to account for
the role that random variation plays in evolutionary processes.

While the significance of genetic determinism is widely debated, I am often struck by
the disjuncture between the way theorists talk about genetics and how it is used in clinical
practice. In a similar vein, I am struck by the way many social scientists and feminist
scholars emphasize the diversity of women, stressing that women as a group cannot be
generalized, yet pay little or no attention to the differences among medical scientists, their
ontological viewpoints or ways of practice. Indeed, based on my field observations of the
HCP clinic, I would argue that genetic ambiguity -- not determinism -- is at the core of
clinical genetics. Inherent to genetic counselling for hereditary breast/ovarian cancer is a
situation where risk and burdens cannot be defined definitively. Detection of a BRCA
mutation, for example, confers an increased risk for breast/ovarian cancer but does not imply
a 100% certainty of developing cancer; it cannot predict when the disease will occur, its
clinical features or whether the person will get it at all. Equally perplexing for geneticists is
how to interpret a negative test result when there is a strong family history of breast/ovarian
cancer. Does this mean there is no family mutation or may it be another gene (interaction of
genes or interaction of genes and the environment) that is responsible for hereditary cancer in
this family? Genetic variances pose another area of ambiguity for them: do these bear clinical

115 It is important to point out that my statements about “clinical genetics” arise from my observations of
medical geneticists at the Hereditary Cancer Program, BCCA and Children’s Hospital, B.C. It is quite possible
that different clinical settings foster a different kind of ‘genetics culture,’ which is more deterministic in
orientation.

116 Genetics, like other scientific disciplines, is not comprised of just one thing. There is population genetics,
molecular genetics, functional genetics, prenatal genetics, cancer genetics and so forth. Accordingly, I worry
that scientists/clinicians in many ways are presented as stereotypically as women were 30 years ago. To speak
as if there is a monolithic culture of genetics, for example, is to take up a discourse that social scientists would
reject outright in other contexts.
significance or are they just nonsense variants of a gene? Thus while we speak of genetics as implying certainty, in actuality the field is a moving target. Indeed, as Mitchinson (1998) writes: “Medicine is a dynamic profession that is constantly evolving” (p.137). There currently exist many gaps in scientific knowledge about the predictive value of different genetic tests. Further, the clinical applications of genetic testing for hereditary breast/ovarian cancer are constantly changing as new knowledge is obtained.\(^\text{117}\)

Ambiguity of clinical practice aside, however, study participants largely subscribed to notions of genetic determinism when interpreting their test results. Most of the women and men I interviewed expressed a sense of fatalism with being a mutation carrier.\(^\text{118}\) The discovery of a genetic mutation appeared to mark a crossing from a theoretical or possible risk to an actual threat. Yet, this view did not come from nowhere. Participants assimilated genetic test results into their life experiences and existing frameworks of knowledge. The genetically defined aspects of hereditary cancer intersected with areas in which the disease was lived and knowledge of breast/ovarian cancer was constructed. Women used experiential knowledge (empathetic and embodied) as basis for deciding whether they were at increased risk even as biomedical information contributed to that knowledge. For most participants, genetic testing confirmed or conferred legitimacy to experiential knowledge acquired and known through family and/or personal experience. For others, it conflicted with family concepts of inheritance based on resemblance or personality traits. For a few participants, knowledge of genetic mutation instigated fear that family history alone did not.

\(^{117}\) Clinical genetics is no different than any other medical discipline in this regard.

\(^{118}\) These findings are in accord with another study, in which study recruits were asked to imagine they were at increased risk for heart disease. Half the participants were told their increased risk was determined by a genetic test, and the other half, by an unspecified medical test. Those who received the genetic test results perceived their heart disease as less preventable. See Marteau & Croyle (1998) and Marteau & Senior (1997) for this discussion.
At the same time, experiential knowledge sometimes conflicted with medical knowledge. Indeed, variations in their experience, family history, life context and life stage led to different responses by participants to the same genetic risk information. Yet, it is important to remember that due to the HCP’s strict eligibility criteria, only individuals and families with an extensive family history of breast/ovarian cancer were tested. Many participants had already experienced cancer themselves. Thus, I would argue most participants did not accept genetic information passively, but drew on their experiential knowledge, as well as social discourses about cancer and genetics in making sense of the test. They did not dismiss the role of social and environmental factors (stress, smoking, diet, pollution, etc.) in contributing to cancer, but interpreted this together with genetic information and family/subjective experience, in constructing meanings about their cancer risk.

To this end, I would argue critiques of genetic testing, based on discourses of geneticization and genetic determinism, are just too stark. Just like medical professionals or historians for that matter, philosophers’ and social scientists’ interpretations of particular events are very much influenced by the period in which they write. Feminist theorists have emphasized for two decades now the importance of understanding the social and political conditions that contribute to health and illness. They also have raised critical questions about the economic and political basis for ‘geneticizing’ cancer, while the social causes are shunted aside (Kenen 1994; Sherwin 1996; Lippman 1998). Although these are important issues, I believe that we need to look at our notions of geneticization critically, just as we need to examine the use of medical technologies critically. (At the same time, I do not wish to demean the critical insights offered by this work). In doing so, I urge a strong caution against arguments that reduce genetic testing to something that simply controls, manipulates
and geneticizes women’s lives.\(^{119}\) There are many reasons why participants proceeded with testing and many reasons why they did not. (Indeed, space limitations preclude me from addressing financial and geographical constraints on pursuit of genetic testing). Each participant’s story was unique, but together participants shared a similar kind of cancer history. These historical pasts led many hereditary cancer families to view genetic determinism not as an ideology but as a biological reality. Many saw genetic testing not just as another form of medicalization, but something that might help them save their lives. To posit that women accept this technology unthinkingly or are victims of geneticization does not acknowledge their life histories and their ways of knowing. It obscures the meanings people bring to this test and fails to honour their agency.

As well as creating the potential for discriminatory practices, two main issues underscore many of the critiques aimed at genetic testing for hereditary breast/ovarian cancer: (1) the test benefits only a very small percentage of women with breast/ovarian cancer (2) it individualizes disease and removes society’s obligation to consider dietary, social or environmental factors which are linked to cancer and other disease (Kenen 1994; Nelkin and Lindee 1995; Sherwin 1996; Lippman 1998; Sherwin and Simpson 1999; Finkler 2000). There is no dispute that BRCA mutations account for only 5% to 10% of breast/ovarian cancers; the vast majority of cancers are currently thought to be multifactorial in etiology. It is also clear that governments have not provided adequate resources to explore social and environmental contributors to the disease, but rather have focused narrowly on biomedical solutions. These decisions are indeed political acts that affect health policy and health care (Lippman, 1998; Sherwin and Simpson, 1999; Sherwin, 1996). Yet, because we

\(^{119}\) At the same time as saying this, I think we should always be attentive to the question: does medical technology control, manipulate and/or medicalize women’s lives in unjustifiable ways?
do not take a broader approach to research funding and the understanding of cancer etiology, it does not mean that genetic testing lacks value. Findings presented here suggest that genetic information is frequently experienced as enabling for properly selected individuals and families. I do not wish to offer a romantic portrayal of genetic technology, but at the core of this dissertation stand women/men who will do anything they can to prevent the onset of the disease. If a biomedical solution helps them (despite the constraints or the poor set of options which follow) they will use it. It is important to remember that women stand to gain as well as lose from medical practices (Mitchinson 1998).

I suspect some of the problems with using the concept of geneticization to critique BRCA testing lies in the conflation of hereditary cancer with sporadic or more population-based cancer. Critics warn that genetic testing will be used as a screening tool, and inappropriately place responsibility on women to ascertain their individual breast cancer risk. "It sets the stage for social control and for "victim blaming" of those who supposedly do not follow sensible advice for their health" (Lippman, 1998: 72). Yet specialists caution that the clinical significance of this mutation in the general population is unknown; in fact, mutations found in this group are likely subject to powerful modifying effects, genetic or otherwise (Ponder 1997; Burke 1999; Peto, Collins et al. 1999). Medical guidelines and advisory bodies have been very clear that BRCA testing of women with sporadic cancer, or those who do not

120 For a few women, however, information about their genetic status posed a threat to their sense of self. I endeavored to represent this through the concept of the 'risky' self. Knowledge that they carried BRCA1/2 mutation thrust them into a state of anxiety, not only about their future health and survival, but also about their ability to be there for others.

121 As previously mentioned, the HCP ceased genetic testing July 2001 because of the threat of legal action by Myriad Genetics over infringement of the BRCA1/2 patent rights. As a result, the HCP has been unable to test blood samples that had previously collected from 276 women. These samples remain frozen and stored at the HCP facilities. In response, the Women's Jewish League of Vancouver has launched a fund-raising campaign to pay for the cost of sending these blood samples to Myriad Genetics, Utah, for DNA analysis. (Myriad charges $3850 for full gene sequencing of BRCA 1 and 2 compared to the $1200-$1500 that provincial labs charge – Dr. Doug Horsman, personal communication). They have titled this fund-raising effort: "Get the Women Out of the Fridge." Clearly, women in this organization think that BRCA1-2 testing has value.
have strong family histories of the disease, is not warranted (Campbell, Mackay et al. 1995; Burke 1997; Koenig, Greely et al. 1998; Pinsky, Culver et al. 2001). This is not a tool for screening the general population, but one that has selected uses. Thus, rather than the medical establishment per se, I would argue that it is the media, biotechnology companies, and even fund-raising organizations that make these exaggerated claims about the widespread benefits of genetic testing. Commercial pressures, as Caulfield (2001) points out, can have a profound effect on how technologies are perceived by the public as well as professionals. Overstated claims about genetic testing also feed into a climate in which widespread fear about breast cancer already exists. Studies continue to show that women commonly overestimate their lifetime risk of breast cancer and the proportion of female death attributable to breast cancer (Black, Nease et al. 1995; Kaufert 1998; Burke 1999). Yet while this is true for the general public and is something that should be addressed through educational endeavors and redressing media hype, I would argue that in hereditary cancer families that fear is well founded. Here, fear of cancer is not an abstract concept based on probabilities and statistics, but arises from watching grandmothers, aunts, mothers and sisters struggle with the disease and, in some cases, having the disease oneself. Again, I stress this point not to glorify genetic technology, but to introduce a more balanced perspective of its potential utility. Further, I fear that the politics and ideology of “geneticization” may detract attention from other thorny issues and potential harms that should be addressed in relation to

122 Despite the concern about potential harms from inappropriate use of genetic testing in the general population, Myriad Genetics, -- the U.S. based firm which holds the patent rights on BRCA1/2 -- will provide genetic testing to anyone who wants it as long as the request comes through a physician. Despite the concern about potential harms from inappropriate use of genetic testing in the general population, Myriad Genetics, -- the U.S. based firm which holds the patent rights on BRCA1/2 -- will provide genetic testing to anyone who wants it as long as the request comes through a physician.

123 In discussing ‘fear,’ we usually cast it in negative terms, i.e. fear is something that be avoided or minimized. Yet, in taking this position we forget the beneficial effects of fear. Biologically speaking, fear is an appropriate response to danger and essential for survival. It would be absolutely foolish if women did not ‘fear’ cancer or any life-threatening illness for that matter (although there are matters of degree). Similar to discussions of geneticization, I believe that we need to take a more balanced approach to discussions of fear. That said, fear mongering by commercial companies in order to sell a particular product to consumers (e.g. genetic ‘screening’ for BRCA mutations in the general population ) is a deplorable activity and should be challenged.
genetic testing (for example, the psychological benefits/harms of genetic testing in adolescents and young adults and the uncritical acceptance of reconstructive surgery following prophylactic mastectomy).\(^{124}\)

Alan Petersen (1998) asks whether and how genetics is changing notions of normalcy. He queries does it create new boundaries between the ‘healthy’ self and ‘unhealthy’ other (p. 69)? While this is a credible concern, I have come to believe that the meaning and power attributed to susceptibility testing for hereditary breast/ovarian cancer are

\(^{124}\) An area that sorely needs critical examination is breast reconstruction. This surgical procedure has become a routine part of medical management following prophylactic mastectomy (Lynch, Lynch and Rubinstein, 2001). Yet, interviews with participants from this study indicate that these surgeries may be problematic. Women complained of infections, bleeding, extensive scarring, severe pain and even having to undergo repeated surgeries. The TRAM (transrectus abdominis myocutaneous) flap procedure, for example, is a complex surgery that involves taking skin, fat and muscles from the abdomen to build a breast mound on the chest wall (Offit, 1998). Complications are frequent and recuperation is lengthy. Thus, the routinization of breast reconstruction raises a number of issues for me. On a practical level: what kind of quality control/monitoring is done on these procedures? Are physicians aware of all the complications associated with them? Do they minimize these or take the time to explain them to the women who undergoing reconstruction? (Conversely, do women actually ‘hear’ what surgeons tell them about these procedures? If not, why not?) I had the sense the women who opted for the TRAM flap surgery, for example, did not understand its full physical consequences. Also, what about surveillance? It is well known that prophylactic mastectomy cannot remove all the breast tissue – scattered breast cells remain at the periphery. Yet, reconstruction makes it impossible to screen the remaining tissue. Is this good medical practice? Further, very little work has been done on the long-term consequences of the TRAM flap surgery. For example, does taking tissue from the abdomen lead to other problems, such as back problems, later in life? Experience with silicone implants has already shown that medical procedures can be far from benign. I do not say this with the thought that physicians should stop performing mastectomy/breast reconstruction and oophorectomy, but rather how can these procedures be improved so they do not disrupt and further medicalize women’s lives.

That said, however, troubling to me is the social message reconstruction perpetuates: that breasts are essential to femininity and womanhood. To be without breasts, it seems, is not to be a woman. In responding to his patient’s decision to have prophylactic surgery (both mastectomy and oophorectomy), the physician of one participant said: “You’ll be just like a guy.” Participants expressed similar sentiments themselves. Sadly, as Audre Lorde (1980) has written in The Cancer Journals, we still do not accept women with breast cancer. We want them to return to their previous state as quickly as possible. We live in a culture that is repelled by physical difference and promotes procedures to mute/hide any evidence of the disease. Of the 13 women who had prophylactic mastectomy for the BRCA 1/2 mutation, only two did not have breast reconstruction. Of these two women, one was satisfied with her appearance and the other could not have reconstruction until she quit smoking. The remaining participants decided to undergo reconstruction largely for practical reasons, but their reasons nonetheless were based on social expectations of two breasted women. I believe this area desperately needs further analysis, as more and more women undergo prophylactic surgery because of genetic testing. I have begun writing a paper on the topic.
greatly exaggerated.\textsuperscript{125} Further, these claims make little room for the positive aspects of medicine. As Reissman (1983), Lock and Kaufert (1998) and Mitchinson (1998) have shown in other contexts, the view of women as simply succumbing to or resisting medical technology is far too narrow.\textsuperscript{126} Similarly, the concept of genetic determinism is insightful but it fails to account for the complexity of women’s relationships to genetic technology. So just as we need to critique the assumptions and ideologies behind particular scientific endeavors, I believe that we need to critique and fine-tune our concepts by which we judge them. This requires that we keep apace of the evolving field of genetics, what claims are made and by whom (scientists, clinicians, the media, public relation agencies, commercial enterprises and/or governments), how these tests are employed in the clinical setting and how they actually play out in people’s lives. It also requires the recognition that genetics, as any medical science, will always be changing. As Keller (2000) illustrates so poignantly in The Century of the Gene, findings from the HCG project itself have challenged the assumptions upon which it was initially based. Gone are the days when scientists viewed DNA sequencing as the endpoint or the key to the ‘secret of life.’ Rather, the map of the ‘human genome’ is now perceived as a tool to explore the more complex gene-environment interactions and gene function.\textsuperscript{127}

\textsuperscript{125} I wish to emphasize that I am talking about genetic testing for hereditary breast/cancer susceptibility here. I think Lippman’s (1998, 1991) concept of geneticization has strong utility in the analysis of other genetic tests such as prenatal testing.

\textsuperscript{126} At the same time, genetic information may be used for discriminatory purposes and we must remain attentive to (and challenge) this effect. But my point is that the potential for discrimination should not override discussions about the medical usefulness of these tests. Burgess (2000) puts it well when he writes: “the moral problems associated with genetic testing are not about genetic testing, but about genetic testing in the context of our current social institutions, attitudes and practices” (p. 6).

\textsuperscript{127} The term, functional genomics, has been coined to represent this new phase of genome analysis (Hieter and Boguski, 1997). It refers to the development and application of global (genome-wide) experimental approaches to assess gene function. The aim is to expand the scope of biological investigation from studying single genes to study all genes at once systematically. By narrowing the gap between sequence and function, it may yield new insight into the functional and behavior of biological systems.
It is a rare and wonderful moment when success teaches us humility and this, I argue, is precisely the moment in which we find ourselves at the end of the twentieth century. Indeed, of all the benefits that genomics have bequeathed to us, this humility may ultimately prove to have been its greatest contribution. For almost 50 years, we lulled ourselves into believing that, in discovering the molecular basis of genetic information, we had found the “secret of life”; we were confident that if we could only decode the message in DNA’s sequence of nucleotides, we would understand the “program” that makes an organism what it is. And we marveled at how simple the answer seemed to be. But now, in the call for functional genomics, we can read at a lead a tacit acknowledgement of how large the gap between genetic “information” and biologic meaning really is. (p. 7-8).

I maintain that it is time to re-evaluate our notions of geneticization based on changing scientific perspective and practice. Indeed, as Alcoff and Potter (1993) write it is very important that feminist scholars continually reflect on “their moral theories against actual practice to see who is empowered and who is disempowered when the theories are put into practice” (p.11). It is the task of feminist ethics to expose and critique oppressive practices, yet at the same time we must be wary of falling prey to our own theoretical dictates.

**Ideologies of breast cancer: the discourse of survivorship**

Just like genetic determinism, meanings of breast cancer are framed by cultural understandings, ideologies and both medical and social constructions of illness (Lantz and Booth 1998; Thorne and Murray 2000; Potts 2000b). Indeed, research has shown that women’s and men’s experiences of cancer go beyond managing the physical aspects of disease progression, treatment and recovery (Lerner 2000; Saywell, Beattie et al. 2000; Thorne and Murray 2000; Potts 2000b). Rather, their experiences are shaped by the meanings and ideologies constructed by the social context in which they live. Rosenbaum and Roos (2000) identify three ideological themes which underlie much of the academic literature and personal narratives on the breast cancer experience: (1) cancer as survivable versus breast cancer as fatal; (2) breast cancer treatment as compromising to women’s identity, femininity
and self-worth; and (3) breast cancer as private. Commonly heard through participants’ accounts were these and two additional ideological themes: (4) information is power and (5) awareness and early detection are key to cancer survival. While each of these ideological discourses contributed to participants’ understandings of breast cancer, the social construction of breast cancer as survivable versus fatal bears particular relevance to hereditary cancer families. In the following, I explore how this theme interweaves with participants’ experiences of cancer and accordingly interest in genetic testing.

In prevailing western society, as Rosenbaum and Roos (2000) point out, women are typically confronted with two competing models of breast cancer. The first model equates breast cancer with suffering, hardship and death. In this context, cancer is a horror story “populated with stalkers, hidden dangers, fears” (Clarke 1999: 120), anatomical time bombs and the like. The second model, which is increasingly supported by the biomedical community, breast cancer support groups and activists, focuses on breast cancer as treatable, survivable and perhaps curable. The recent shift (and to which I would add pressure) to depict breast cancer as beatable, however, is accompanied by the view that a positive attitude and fighting spirit will create a better health outcome (Wilkinson and Kitzinger 1993; Morris 1999). Military metaphors are common as individuals are encouraged to “fight,” “wage war” and “win” against this disease; indeed dominant discourses have shifted to emphasize ‘cancer survivors’ versus ‘cancer victims’ (Batt 1994; Lupton 1994; Luker, Beaver et al. 1996; Lantz and Booth 1998). While women respond to both these models in different ways, each reflects the reality of cancer to a degree. Many women survive breast cancer; in fact, since 1985 breast cancer mortality rates have declined by 25% among women aged 50 to 60 due to early detection and improved therapeutic regimens (CCS/NCIC, 2002). However, it is also the case
that many women die from breast cancer. Thus, as Rosenbaum and Roos (2000) advise “part of the lived experience of breast cancer entails trying to reconcile these two competing meanings” (p. 154). Further, how women think about breast cancer is not only affected by perceptions of survivability, but also strongly influenced by methods of treatment and the effect this has on the body.

Study participants negotiated the personal and particular within these ideological frameworks. Some viewed cancer as potentially manageable if detected early enough. Yet, for many, the image of cancer as uncontrollable and fatal still held sway. Interpreted within their family contexts, the understanding that breast/ovarian cancer equaled death reflected the reality many participants had faced. They had acquired knowledge of cancer, its particular manifestations, the side effects of treatment and the likelihood of survival, from personal experiences in living with or caring for relatives who have had the disease. They also acquired it, although less directly, through family stories passed down from one generation to the next. These experiences are profoundly powerful in shaping meanings of breast cancer. Recall Lorraines’s comments from Chapter 6: “The survival rate [from breast cancer] is really good and they [physicians] are quite confident if they find it early people survive. It’s just in our family that was never our experience. Everybody who got it died quite quickly actually.”

Thus, the ‘survivorship model’ reflects a tension between lived experiences articulated by many women from hereditary cancer families and a more recent ideology that challenges the ‘cancer equals death’ tradition. Yet, at the same time, the ideology of cancer as beatable is one to which many participants aspired (via genetic testing, mammography, clinical and/or self-breast exam, that is methods which improve ‘early detection’ as well as
prophylactic surgery). To this end, I agree with Saywell, Beattie and Henderson (2000) when they write that the popular images used to conceptualize breast cancer are limited. “The paradigms of representation discussed detract from the many ways in which women might experience breast cancer” (p. 51). While the survivorship model is a valuable (and for most a very desired) alternative to the fatality cancer model, I would argue that it fails to capture the complex reality of many peoples’ lives. Conforming to an individualistic ethic, it promotes the view that if a person fights hard enough she too can survive cancer. Its focus, while intended to empower, erases much of the pain, struggle and difficulties associated with living with cancer. Further, in placing such emphasis on this one outcome, do we inadvertently negate what it means to live with or live with a person(s) who has this disease? Indeed, neglected in this ideological discourse are the stories and experiences of those who have witnessed the suffering and/or death of a family member who has had cancer. We tend to speak of survivor in the singular; that is the person who has had cancer and has “beat it.” Yet in hereditary cancer families (like all cancer families) there is another group of survivors. Particular to this group are the family members, siblings, partners and friends of those who have had cancer; the people left surviving after a loved one dies. They live on with the emotional experience of this particular illness as well as with the knowledge of family legacy that might befall them or their children. In the context of familial cancer, not everyone

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128 The over-sexualizing of breast cancer adds another layer of complexity to this issue. For good discussions on this aspect of breast cancer see Thorne and Murray (2000); Sayell, Beattie and Henderson (2000); Hallowell (2000) and Potts (2000).

129 At the same time, it is important to keep in mind that the individuals/families I interviewed were among the first to be tested for the BRCA1/2 mutation and had extensive histories of the disease. Clearly, participants’ accounts and my interpretations/constructions might be quite different if the preponderance of cancer in these families was not so great.

130 My thinking on this issue was sparked by a comment made by a community attendee at the “Living Well with Cancer Conference,” Kelowna, B.C., February 15-17, 2002. Struggling with cancer, she said that she did not worry so much about herself but about her daughter who will survive her.
experiences death related to cancer as over. Rather, as participants’ accounts illustrated, it is a critical point of reference that permeates people’s lives: past, present and future.

In looking at how women weigh dominant cancer ideologies against their own experiences, I also wish to revisit some of the clinical and biological findings related to this disease. It has been recognized for some time that there is no single cause of breast cancer; rather scientists suspect that it is the interaction of a number of factors (age, hormones, diet, substances in the environment and genetic make-up) that promote the development of the disease (Olivotto, Gelmon et al. 1995; Offit 1998). Further, breast cancer is not just one entity but many. As Olivotto, Gelmon and Kuusk (1995) explain, ductal carcinoma is the most common type of breast cancer and consists of tubular, mucinous, colloid, medullary and inflammatory subtypes. There is also lobular carcinoma, squamous carcinoma as well as cancers that begin in areas outside the ducts and glands: sarcomas, lymphomas and cytosarcoma phyllodes. Some breast cancers are associated with worse prognoses and require more aggressive therapeutic intervention than others.

With this as the ‘scientific context’ then, participants’ accounts about the frequency and extent of illness in their families have led me to query whether we might be dealing with a different kind of cancer here. Is hereditary cancer associated with a different biological/genetic mechanism that leads to a more aggressive type of disease?\textsuperscript{131} What about families in which there is a strong cancer history, but no BRCA mutation is found? Are there other cancer predisposing genes in these families that have yet to be discovered? How do genetic determinants interact with environmental, dietary or lifestyle risk factors? I raise these questions to illustrate that medical knowledge about breast cancer and breast cancer

\textsuperscript{131} After proposing my ‘hypothesis’ to Dr. David Huntsman, a geneticist at the BCCA, Vancouver, he told me that there is some indirect evidence to support the notion that some BRCA mutations are associated with more aggressive cancer. However, further studies are needed to establish this is indeed the case.
genetics is vastly incomplete. I also raise them to re-emphasize the point that women from hereditary cancer families may experience cancer physiologically — as well as socially — in very different ways from the general population. Add to this the many variables through which women experience their bodies and medical choices (age, socioeconomic status, location, access, age and so forth), then survivorship/death discourse hardly begins to address the complexity of how women from hereditary cancer families frame their knowledge of breast cancer and genetic risk.

Conversely, the experience of cancer and likewise interpretation of genetic risk is not a static process but one of evolving and changing perspectives. For example, participants’ responses to the disease, and the toll it has taken on their families’ lives, partly reflects the historical reality of the cancer before more successful treatments became available (Rosenbaum and Roos 2000). Cancer treatment and methods of detection have improved considerably in the last 10 years and will hopefully continue to bring about better results. This in turn may lead to a different view of cancer (treatable vs. fatal). The image of breast cancer as a fatal disease may also begin to shift as women who are mutation carriers engage in aggressive surveillance and/or have prophylactic surgeries. If these procedures prove efficacious and cancer is “prevented” or cancer survival begins to improve in these families, then the ‘cancer equals death’ model will likely break down. Thus, the actions taken by the present generation of mutation carriers may result in cancer as being perceived as less of a threat. Without witnessing breast cancer directly, future generations from hereditary cancer families may not see the need to intervene so early and decisively. Accordingly, the perceived utility of genetic testing may change or take on a different meaning altogether.

132 A recent education campaign launched by the Vancouver AIDS Society prompted me to think about this. It has been known for some time that HIV infection rates are increasing in young gay men. One of the reasons
In sum, prevailing social discourse continues to embrace two main ideological representations of cancer: cancer as survivable versus cancer equals death. While participants situated their accounts in relation to either or both of these dominant discourses, their experiences appear more complex than the binary image portrayed by these models. Indeed, I would argue that in hereditary cancer families, the traditional divisions between cancer survivor and victim are frequently blurred as knowledge of cancer and cancer risk permeates families and extends across generations. Participants negotiated their experiences in terms of victims and survivors, as well as victims as survivors and survivors as victims and other representations that integrated the self with others. At the same time, in this risky area where selfhood and life are threatened, women from hereditary cancer families continued to challenge the cancer equals death model through individual actions. At the core of participants’ accounts were women who perceived cancer as a tangible threat to their embodied selves. For example, in contrast to the breast-conserving surgery typically used for localized or early stage cancers, some affected participants, as well as those who were mutation carriers but healthy, elected to have prophylactic mastectomy and oophorectomy. While this action may seem drastic, especially in the face of uncertain benefit, these women based their decisions on practical considerations and knowledge of cancer in their families’ lives. It is also important to remember that this action is shaped by cultural discourses that surround cancer in general. It resonates with both a biomedical and social discourse, which given for this trend is that those born in the last 20 years have not observed the devastating suffering and fatality caused by AIDS. Further, the development of multi-cocktail drugs has shifted the image of this disease (in Western society anyway) from an illness that is fatal to one that is treatable. It has been posited that young gay men are more willing to take risks because of this. In response to this concerning trend, the AIDS Society has launched a recent campaign stressing quality of life issues. In particular it has focused on the debilitating side effects of living with the AIDS cocktail drugs. This situation led me to wonder whether in the future, in a similar way, young women from hereditary cancer families may not see breast cancer as such a serious disease. If measures taken by their mothers, or other female relatives, reduce the incidence of breast cancer then fear about the disease may begin to abate.
promotes the belief “the safest strategy is to remove as many potentially cancerous cells as possible,” (Lerner 2000: 43). As Thorne and Murray (2000) remind us, the medical processes involved in diagnosing cancer and recommending certain treatments over others are also social acts. These, too, are embedded in a particular ideologies and ways of knowing.

The ideology of choice; the context of responsibility

In medicine, bioethics and in other areas of life, western society tends to deify the ideology of choice. At the most general level, choice invokes the notions of equality, equity and individual liberty (Keller 1992). It is seen as providing options, granting greater freedoms and providing new directions for people based on their values, beliefs and where they are situated in their lives. It is a democratic and egalitarian ideal and commonly viewed as both an individual right and social good. As Stingl (1996) writes, “What makes human beings the interesting, valuable creatures that they are is the fact that they are able to think about and choose the ends towards which they will act...Whatever particular mix of such ends a person might choose to pursue, the important thing about people is that they are able to make such choices; they are able, that is, to determine the goals and aims that give structure and meaning to their individual lives” (p. 8). Indeed, respecting the choices of health care “consumers” is a critical component within contemporary health care reform movements (Brock and Daniels 1995). It underscores the philosophy behind patient-centred approaches to health care (Stajduhar 2001).

133 While I have intentionally kept discussion of prophylactic mastectomy to a minimum, it is important to remember that this procedure is not new to genetic testing. Women from hereditary cancer families have been asking for prophylactic mastectomy for some time. Prophylactic oophorectomy has also been recommended to women with strong family histories of ovarian cancer since the late 1970s (Lynch et al, 1979). Indeed, one of the purported benefits of genetic testing is that information about mutation status will prevent unnecessary surgery. Recall that three participants in this study underwent prophylactic mastectomy based on family history alone. Of the three, only one was later found to be a mutation carrier. Access to genetic information, then, might have prevented the two participants from undergoing surgery.
Within this context, genetic testing is typically seen as a technology that will aid individual choice and decision-making through the provision of information. Respect for the principle of autonomy is understood as individuals' rights to choose and direct their health care based on their own values and notions of welfare (Sherwin, 1998). Seen from this vantage point, informing persons about the benefits and harms of genetic testing not only protects their rights as autonomous decision-makers, but also empowers them to exercise personal control over their lives. Indeed, genetic testing is frequently viewed as a technology that can inform medical and personal life decisions. This, in turn, is enacted through self-determination or the freedom of choice.

While genetic testing offers hereditary cancer families new options for managing their health, participants talked about choice in different ways. For the majority of participants, genetic information provided choice. They valued genetic information both for the sake of knowing and for the control over their life that this knowledge implied. They perceived information about genetic risk as allowing them to be more proactive about their health or to avoid surveillance strategies if they tested negative. They saw genetic testing as beneficial -- providing choice -- regardless of who initiated it. Yet, genetic testing is unlike other medical technologies in that genetic information about one person automatically has implications for others. Indeed a few participants said that genetic testing by other family members denied them the opportunity for choice. They felt forced to live with information that they would rather not have and from which they could not escape. Still others talked about 'no choice' in that their decision to pursue testing stemmed from a duty to provide others with the information. Parents, in particular, felt obligated to undergo testing for children, grandchildren and future generations to come thinking that genetic information

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134 Testing for sexually transmitted or infectious disease bears some similarity in this regard.
might possibly help them. Likewise, some adult daughters were tested solely to satisfy their parents. Also found in the study were examples of coercion. When one person puts pressure on another to be tested, however well intentioned, it minimizes the opportunity for choice. Further, the choices made by one generation of family members may either expand or limit the choices available to future generations, especially if health care or social policies around genetic testing change.

Findings from this study also showed that the decision to seek testing and the information obtained elicited choices at other levels. If found to be a mutation carrier, for example, some women felt compelled to undergo prophylactic surgery. These women did not describe this as a choice per se, but as the only option available to them. This was often influenced by personal experiences with the disease, knowledge of others’ experiences with the disease and faith (or lack of) in mammography and medical surveillance. Others saw genetic testing as providing ‘choice’ in that they would have sought prophylactic surgery based on family history alone. Knowing that their mutation status allowed them to better determine whether this course of action was necessary or could be avoided. Alternatively, genetic test results gave other women access to health care services—and thus more choice—than they had experienced previously. These women had been denied services (mammography, for example) on family history alone. Still others rejected genetic testing altogether and made the decision to seek alternative methods in hopes of lessening their cancer risk.

Traditional philosophical thinking, as well as western social discourse, has typically stressed the ideology of free will and individual autonomy with respect to choice (Dodds
For example, in the context of genetic testing, emphasis is placed on the role of individual choice in the kinds of interventions that genetic information makes possible. This narrow focus on the individual, however, overlooks the deeply relational aspect of choice and self. As well, it ignores the social circumstances and power relations that influence the choices we can make (Dodds, 2000; Sherwin, 1998; Sherwin and Simpson, 1999). Indeed, study findings indicate that choice is not just an objective activity based on an individual interest alone, but is a process that emerges and is defined in relation to others. Choices around testing involved decision-making about personal health, but also intersected with concerns for children, extended family and unknown others. When contemplating testing, women with children frequently described their decisions as influenced by thoughts about their offspring. Participants were concerned with staying healthy and being able to fulfill their parenting roles. Others sought testing so that they could provide offspring or other family members with information relevant to their risk status. Participants also spoke about wishing to help society generally by participating in research for known and unknown others. Thus, the choices many participants made were not only about their own health, but also about the health of their offspring, future generations to come as well as society in general. Rational choice reflected participants’ values and goals not just as isolated individuals but also as selves in relation to others. It existed along a continuum from self-care to concern for others. This observation also holds for those who elected not to be tested.

At the same time, the relational aspects of choice cannot be considered separate from other aspects of social identity (age, economic class, ethnicity, dis/ability, location, and other socially marked differences). This study illustrates, for example, how life stage influences

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135 This is, in turn, is shaped by a historical context in which individuals sought freedom from controlling state or institutional power. I thank Dr. Michael Burgess for bringing my attention to this point.
how genetic information is perceived and what kinds of choices it presents. It shows how ethical understandings of how we should live our lives and how we should deal with moral issues may shift with human life stage. For example, for younger women, knowledge of a positive test result raised specific moral questions with respect to reproduction. (1) Do they have children, knowing that they could pass the mutation onto their offspring? (2) Do they have children knowing that they themselves are at high risk for cancer? Some decided to have children at a younger age than they might otherwise with the intent of have prophylactic surgery afterward. Obviously, reproductive decisions were not as great a concern for women in their middle years. Yet, very important for them was the provision of genetic information to others in their family. At the same time, because of their age, cancer was commonly viewed as a greater threat to this group. These participants did not view cancer as something that might happen in the future, but something that would happen any day. Consequently, the need to choose between ongoing surveillance and prophylactic surgery became more pressing. Yet, the choices open to both younger and older women may be less ideal than the choice ideology presupposes: How good are the screening services in different locales? How accessible are they? Is prophylactic surgery really effective in preventing breast and/or ovarian cancer?

Feminist discussions of self-determination have drawn attention to the social context in which choices are made. Sherwin (1998) for example, cogently argues how oppression, inadequate socialization, access to program and limited health-care funding affect the choices offered to patients. Dodds (2000) adds to this discussion:

These factors also influence the patient’s (and physician’s) subjective understanding of those choices and shape the capacities of patients of patients to resist, inform, or control the process of obtaining information and making a decision. Sherwin thus pushes against an identification of autonomy with voluntary choice and toward an
understanding of autonomy in health care as aligned with contextualized rational choice" (p. 226).

Rothman (1998) holds a similar viewpoint, stressing that unrestricted choice is a misnomer. In her words: “Free choice is never free. It’s a choice made in context and not a context of one’s choosing.” (p. 248). Indeed, participants who sought testing, as well as those who did not, often framed their choices in response to specific circumstances and constraints that limited the very notion of choice.

Choice ideology also needs to be considered within the context of responsibility to others. In Moral Understandings: A Feminist Study in Ethics, Walker (1998) develops an “expressive-collaborative” approach to ethics in which she locates moral life in practices of responsibility. Morality, according to Walker, converges around notions of identity, relationships and values, as well as people’s understandings of their own and other’s responsibilities. She writes: “In making each other accountable to certain people for certain states of affairs, we define the scope and limits of our agency, affirm who in particular we are, show what we care about, and reveal who has standing to judge and blame us” (p.16). Indeed, findings from this study identified ‘responsibility to others’ as a key facet of the choices and decisions participants made. Responsibility to others was embedded in participants’ accounts about their choice and decision to seek testing (or not), what to do about the information, as well as whom to tell. In explaining their motivation to disseminate this information, for example, both women and men were influenced by their responsibilities, obligations and commitments to others. Many held the view that family members had a right to genetic information especially if it might improve another’s welfare. As well, participants disclosed information regarding genetic testing in relation to perceived responsibilities as caregivers. In some cases, this care-based responsibility even extended to family members
women personally did not know. Two other studies also show rates of disclosing genetic test results to family members are high. In assessing the degree of communication of BRCA results to sisters, Hughes et al. (2001) reported that 85% of carriers communicated their test results to their sisters. (All participants in the study were the first index family members to undergo testing and had already been affected with breast or ovarian cancer). In a survey assessing communication patterns in high-risk families, Julian-Reynier et al. (2000) also observed that women showed a high level of willingness to disclose personal genetic test results to others.

Yet, as Walker (1998), Smiley (1992) and others have articulated, conceptions of responsibility (just like choice) are influenced by social meanings and practices. Thus, there is a danger that social characterizations that depict women as natural “carers” may make women, in particular, feel that they are morally obligated to share this information with others. Scholars have consistently shown that women are assigned the lion’s share of care giving within the family (Graham 1985; Stacey 1996). They bear responsibility not just for maintaining their own health, but safeguarding the health and welfare of their children and partners. By providing information about a woman and family’s risk status, genetic testing may also contribute to the gendering of responsibility. Indeed, this study showed that women were more likely than men to share information outside the nuclear family. The usual power imbalance between physician and female patient (Asch and Geller, 1996) or between certain family members, may be exacerbated by the promise of control that genetic knowledge implies. By focusing on the individual, genetic testing promotes the tendency to attach blame to non-action or a refusal to act. Thus, rather than promoting individual decision-making, women found to have a genetic mutation may perceive themselves as obligated to disclose
information they are not comfortable with sharing. Moral dilemmas may also arise from having to communicate this information to people whom the tested individual does not know or is estranged from (Green, Richards et al. 1997; Sachs 1999; Hughes, Lerman et al. 2002). Thus, the responsibility ensued by genetic testing may been seen to reduce some individuals' choices or control over their lives.

We need to be wary of the gendering of responsibility and recognize the dominant discourses that may push genetic testing in this direction, but at the same time the research findings illustrate that women's participation in testing and their dissemination of this information should not be viewed solely as evidence of disempowerment. These activities might also allow for a more complex expression of self-governance. They may provide a space in which women are active moral agents in relation to both the self and the self in relation to others. It is through responsibilities to others, as Walker (1998) writes, we define ourselves as moral beings. Responsibility is critical in shaping interactions and shaping life worlds. Indeed, many individuals in this study viewed genetic testing as a way do 'do right' by their families. It allowed them to obtain what they perceived to be valuable information for their kinship. In sharing this information with others, it provided them the opportunity to strengthen interpersonal ties. Indeed, responsibility to others and choice is grounded in self-identity. As Nelson and Nelson (1995: 136) observe:

Choices made...in a very important way determine who we are, who we have been, and who we will be as moral people; this gives choices their proper weight, and defends us from the kind of self-deception that is sometimes a part of having to decide in morally difficult circumstances.

Thus, rather than reflecting two polarized positions, responsibility to others and choice are inextricably intertwined. In fact many times, participants appeared to be enacting moral agency through their responsibility to and choices made for others. At the same time,
however, it is important to recognize that testing for a BRCA mutation and dissemination of genetic information involves a gender-specific component in its impact on people’s lives. Women are more likely than men to undergo testing and likewise assume a disproportionate responsibility for disclosing this information. In the bioethics literature, scholars tend to assign responsibility for disclosing genetic information generically, but it is women who bear the brunt of this task. We must be aware of this, as well as the social relations or political conditions that may fashion or constrain this response. We must question whether social and medical expectations will hold women increasingly responsible for the outcome of these tests. Yet this is not a static situation. We tend to think about choice in terms of an outcome or an event. It is a noun. It is a thing. But choice, and the responsibilities in which it is embedded, involves a process that shifts, evolves and changes over time as new commitments are made and old ones are sustained, renewed or broken.

In sum, while choice ideology is usually equated with individual self-interest or self-direction, findings from this study indicate that choice divorced from relationship is incomplete. Further, responsibility to others affects choice in a way that is not captured by traditional approaches that emphasize the individual and specific medical interventions. Just like autonomy and integrity, this study suggests that responsibility is a value that intersects with the formation, negotiation and continual transformation of self. Moreover, in genetic testing responsibility to others is not limited to the present or to known people. Responsibilities may also include choices taken for future generations. At the same time, we also need to be aware of the dark side to responsibility. While some women may embark on testing for the benefit of their family, others may experience their efforts as oppressive and

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denying them choice. Further, not everyone perceives the ability 'to choose' as a good thing, especially if there is no cure or definite means of prevention (Kenen, 1996). The choice to be tested may limit people’s ability not to know or be faced with the burden of knowing in a culture where knowing is so highly valued. Wexler stresses this point with respect to predictive testing for Huntington Disease: “Our experience with Huntington’s has shown that some things may be better left unknown” (Murray 1994: 30).

**Relational selves**

The previous sections situated participants’ accounts of genetic testing for hereditary breast/ovarian cancer within the broader context of three dominant ideologies: genetic determinism, breast cancer survivorship and choice. I addressed how people’s experiences sometimes cohere, as well as conflict, with theoretical discourses and assumptions about genetic technology. By focusing on the values and commitments people brought to genetic testing, I also sought to assess the influence of genetic information on expressions of moral agency within these ideologies. Some of these findings – in particular, the enactment of moral agency in relation to others – challenges the simplicity of biomedical decision-making as traditionally conceived.

In the remaining part of the chapter, I further explore conceptions of moral agency and understanding of self through central ideas presented in the preceding chapters: relational selves and experiential knowledge; relational selves and moral/social identity; relational selves and responsibility. Participants’ accounts not only shed new light on how genetic information is experienced, but serve as a valuable site for philosophical reflection and insight.
Relational selves and experiential knowledge

Feminist critiques of mainstream theories of autonomy are directed primarily at the image of the self-portrayed. The individual in liberal thought tends to be a disembodied, de-gendered, disengaged and an unencumbered social self with individual rights and interests (Friedman 1997; Meyers 1997; Walker 1998; Porter 1999). “In Rawls’ theory, hypothetical people are rational choosers, not moral selves with specific needs, interests and bodies.” (Porter, 1999: 12). Yet, findings from this study illustrate that the self is situated contextually, historically, socially and culturally; that family ties, affiliations to communities and social groups contribute hugely to moral identity. By observing how people come to genetic testing and respond to genetic information, we gain further insight into the deeply relational nature of human lives.

Indeed, the notion of the relational self adds to our understanding of genetic testing for hereditary breast/ovarian cancer in important ways. For one, it moves the focus of discussion beyond quantitative analysis on “outcomes” to how people view, interpret and live with genetic risk information in their everyday days. It gives depth and texture to how cancer history and involvement with affected relatives contribute to experiential ways of knowing cancer. In this study, most participants acquired knowledge about hereditary cancer from living with a person(s) who suffered from or who had died from the disease. This kind of empathetic knowledge was affected by the kind and amount of shared experiences with a relative(s), the variability of a relative’s illness trajectory, the extent of suffering witnessed and the sheer number of family members who had died. For others, knowledge of hereditary cancer was solely a matter of what had been shared through family stories and hearsay. There had been little or no contact with the people who have had the disease. Although these
participants possessed knowledge of their family legacy, it was far less personal. Other women had been afflicted by cancer themselves; their knowledge was embodied in addition to being empathetic, that is knowing about cancer through others' experiences. These situations illustrate that experiential knowledge about cancer is obtained within relationship and community. Experiential knowledge, write Dalmiya and Alcoff (1993), is about knowing how versus knowing that. To this, I would add it is also about knowing with. Knowledge is not an objective activity based on rationality and 'pure fact' but is a process that emerges and is constructed in dialogue with others (Alcoff and Potter 1993).

Further, experiential knowledge is hardly neutral but has a profound effect on illness representation, decision-making as well as risk perception. Thus, while the detection of a BRCA1/2 mutation may indicate similar medical risk for two individuals, they may interpret their risk for cancer differently based on their experiential knowledge. This area is worth exploring further, as a number of studies have shown that inaccurate and/or exaggerated perceptions of risk persist even after genetic counselling (Lloyd, Watson et al. 1996; Cull, Anderson et al. 1999; Elwood 1999; Rees, Fry et al. 2001). However, little formal attention has been paid to the relational and subjective experience of family history in genetic counselling beyond establishing the family pedigree (Rees et al., 2001). This study indicates that degree and intensity of these experiences may account for some of the variation in participants' responses to genetic information and interpretation of their genetic risk. A more detailed analysis of subjective experience and sensitivity to ways of knowing may provide a means of assessing how people from hereditary cancer families think about and internalize genetic risk information. This, in turn, could inform the development of different counselling
approaches to risk communication. I will examine the clinical implications of this issue in the next chapter.

Relational selves and moral identity

This study is unique in its focus on how genetic testing intersects with people’s understandings of self and their moral identity. As Marteau, Duijn and Ellis put it, “People’s identity or image of themselves is derived from how they view themselves as well as how others view them” (1992: 188) and this view can be influenced to a degree by health status. Self-direction, responsiveness to others and understandings of one’s and other’s responsibilities are tasks inherent to both moral-identity and social life but may be altered by knowing one is at genetic risk for a life-threatening illness.

I used dimensions of self in three areas—the embodied self, the relational self and the social self—to explore this topic further. However, I wish to reinforce the point made earlier that these three aspects of self are separated for heuristic purposes only. My aim here is not to simplify or dissect ‘the self,’ but to show how aspects of self contribute to the complex and multi-layered nature of participants’ responses to genetic testing. In doing so, I have tried to avoid the pitfall of characterizing genetic testing as something that is all good or all bad, or dichotomizing participants’ responses as an example of acquiescence or resistance. Rather, this study takes as its starting point that women/men are willing to use medical technologies if seen as useful. Although a few participants embarked on genetic testing without giving it much thought, most used the information to try and improve their own lives and the lives of their children, siblings and other family members. At the same time, however, participants’ ‘choices’ were constrained by the options available to them. (As a mother of a 24 year-old daughter stated, genetic testing provides useful information but the choices it creates are
tough — prophylactic mastectomy and oophorectomy — especially if one is young. Clearly, interest in genetic testing would not take the form it has if a cure, or more gentle treatments, were known).

Accordingly, the construction of relational self is inseparable from the construction of the embodied self, the embodied self from the social self and so forth. For example, findings presented in Chapter 6 repeatedly showed that the decision to pursue genetic testing (or not) reflected choices defined and made within the context of family and community. In addition to self-care, obtaining genetic information allowed participants to express their identities as mothers, daughters, sisters as well as fathers and concerned citizens. In a similar way, participants' responses to genetic information demonstrated the intermeshing of these different aspects of self. Participants used genetic information to direct their own health care, as well as to fulfill relational duties as parents and to inform others of their potential risk. Linking these different aspect of self together were notions of responsibility. Hallowell (1999) makes a similar observation:

Genetics is not about individuals, it is about biological relationships... To have information about oneself, is to have information about others... [and] so have responsibility for others' risk” (p. 606).

The integration between the embodied and relational self was also clearly seen in the responses of those who tested negative for the mutation. Many expressed relief in knowing they did not carry the mutation, but felt ‘guilty’ or worried about family members who did. The integration between the embodied and relational self was embedded in younger women's reproductive decision-making. Critical to their decision-making were questions about their ability to sustain a parenting role, as well as the worry that their future children might inherit the mutation from them. Genetic testing for hereditary breast/ovarian cancer is not unique in
this regard. In her study on reproductive decision-making in Huntington Disease, Downing (2001) found that reproduction presented two main concerns for individuals at risk for HD: (1) the risk of passing the mutation onto the child and (2) the risk of developing the disease as a parent and becoming unable to mother or father effectively. However, in comparison to HD, those who were tested for the BRCA mutations expressed more faith in future technological advances. They thought that a medical cure for cancer might be found by the time their children reached adulthood. Thus, unlike those in Downing’s study, none of the younger participants felt compelled to forego having children based on their mutation status alone. Yet, this information did impact how younger participants perceived their identities as potential or future parents.

Relational selves: biological relatedness and social identity

This study has emphasized the critical role families and family history plays in shaping knowledge about hereditary cancer and cancer risk. The previous discussions have been shaped by a particular characterization of family as “relationships marked by shaped histories born of close and ongoing contact” (Nelson and Nelson 1995). As Nelson and Nelson (1995) point out, however, there is a second sense of family. This sense of family can be distinguished from the previous one in that it is more abstract; it refers to a family name or a genetic line whose members extend across time and space. Yet, if one holds to a notion of a relational self as critical to who we are, this impels us to ask whether personal identity would be altered by knowledge of new relations/extended family, albeit it only by ‘blood’? In other words, does genetic knowledge have the potential to change the way people conceptualize their selves by changing their place among family generations or within a biological/genetic kinship?
I follow Elliott’s (2001) lead in dividing this question into issues of family identity and kinship on the one side, and issues of social identity and community on the other. This question did not pose a significant theme in this study, but a few examples warrant comment here. Recall Sara’s story from Chapters 5. Through genetic testing, she learned about her family history solely by chance and subsequently about extended family (aunts, uncles, cousins) that she had never met. Several times during our interview, she spoke about how this information disturbed her. The discovery of her distant family caused her to re-think her kinship and where she fit in within an extended family structure. In learning about her genealogy through genetic testing, Sara was compelled to renegotiate her identity both in terms of a newly discovered family and a disease for which she was at risk. Her knowledge of her family’s past and future changed because of genetic information. Knowledge of genetic risk may also affect the ways in which people think about and act upon their biological connections to others. Sara, for example, spoke about tracing a half-sister (who had been put up for adoption at birth) because she tested positive for the BRCA1 mutation. Obviously, this kind of communication would have a dramatic impact on her half-sister’s understanding of her inheritance, her biological and social identity and in turn understanding of self. Further empirical work is needed to determine the consequences of this kind of disclosure.137

Genetic information also has the potential to influence a person’s social identity. Recall Anna’s story from Chapter 7. Detection of an Ashkenazi Jewish mutation affected not only her understanding of her embodied risk for breast/ovarian cancer, but her family

137 Again, this situation is not unique to genetic testing for hereditary breast/ovarian cancer. In a focus group study with people who were at risk for Huntington Disease, Sue Cox and Michael Burgess also noted that one of their participants talked about finding and informing an “adopted out” sibling of his genetic risk for the disease (personal communication).
relationships and her perceived membership within a particular social group. Was she Jewish or not? Clearly, the way a person is genetically constituted has played a serious role in various ethnic, religious, social and political structures (Elliott, 2001). As Brunger and Bassett (1998) put it: "Assumptions about heredity provide some of the most powerful and persuasive determinants of individual and group identity" (p. 30). At the same time, however, people's responses to knowledge of an ethnic mutation will vary. I suspect that not all people found to have a mutation specific to Ashkenazi Jewish ancestry, for example, will view this as significant in determining who they are. Anna's response to her test appeared to be shaped by her personal history and being excluded from a group to which she longed to belong.

Genetic testing for hereditary breast/ovarian cancer differs from predictive testing for single gene disorders (e.g. Huntington Disease, sickle-cell anemia, Tay-Sachs disease) in that there is not a single mutation but a variety of mutations on Chromosome 17 (BRCA1) and Chromosome 13 (BRCA2) that increase susceptibility to the disease. Some of these genetic mutations have been linked to founder populations; that is they are unique to specific ethnic or geographically situated groups. For example, in addition to the three mutations that are specific to Ashkenazi Jewish ancestry, there are specific mutations connected to founder populations in Quebec, Poland, Scotland, Iceland, Finland and others (Tonin, Mes-Masson et al. 1998; Gordski, Byrski et al. 2000; Liede, Cohen et al. 2000; Neuhausen 2000; Sarantus, Huusko et al. 2000). How these genetic mutations are perceived, negotiated, managed and used within context of inheritance and ethnic or cultural identity is open to question. This may be a nonexistent issue or one of scale, but research in this area is vital for an adequate understanding of the personal, social and political dimensions of genetic testing. At the same time, it is essential to guard against the possibility of stigmatization or discrimination based
on genetic characteristics. Cancer genetic studies which focus on identified populations must be conducted with caution so that the disease is not racialized by new genetic information.

Relational selves and responsibility

This investigation has contributed to the understanding of responsibility in different ways. As previously noted, responsibility to others underscored participants’ choices and reasons to get tested, what they did with the information and to whom they disclosed their test results. Responsibility was not viewed in an isolationist way (my responsibility is to leave you alone and yours is to leave me alone), but rather was rooted in specific relationships. Genetic information was viewed as information about the (biological) family and as such, most participants perceived that they had an obligation to make this information available to their kin. Some have written that genetic information is no different from other kinds of medical information (Holm 1999). However, in practice genetic testing is seen as a family affair and sharing of information is extensive within this realm. Responsibility to others also shaped some people’s decision not to get tested: they saw the test as having the potential to cause a lot of anxiety and wish to spare their family this worry.

In keeping with Walker (1998) and Lloyd (2000) and building on work I conducted with Michael Burgess (Burgess and d'Agincourt-Canning 2001), this study suggests that practices of responsibility go far beyond contractual or formal relations, but are intrinsic to the shaping and understanding of our moral selves. In our paper, Burgess and I used the term ‘relational responsibility’ to describe this concept further. We defined relational responsibility as “a sense of moral self that is largely defined by the responsibilities personally acknowledged as arising from particular relationships. Simply put, this notion is characterized by who we want to be in relation to others” (p. 363). Relational responsibility
points to those commitments, values and practices that define personal relationships and
order lives. It is about revealing relationships that exist within a time and place. It is bound
up with the meanings people construct about their sense of self, moral identity and social
relationships shared with other persons. At the same time, it is important to recognize this
construct does not apply to every interaction (nor should it). It fits some forms of
relationships better than others and will vary within and across relationships. Relational
responsibilities in the context of parenthood, for example, will be quite different than those
that arise out of professional obligations or responsibilities derived from friendship.
Moreover, people will experience these in diverse ways.

Philosophical thinking about moral responsibility has tended to revolve around
abstract discussions of praise, accountability and blame (Smiley 1992; Walker 1998; Lloyd
2000). Indeed, philosophical conventions have favored a high level of abstraction,
generalization and uniformity as a basis for theoretical rules. A theoretical approach to
responsibility, for example, seeks to establish objective criteria against which the actions of
an individual, group or even society can be judged morally acceptable or blameworthy.
Walker's (1998) description of a theoretical-juridical model to morality clarifies this point.
She writes:

It is assumed that morality is essentially knowledge, or that philosophers can
reflectively extract a core of knowledge specific and essential to morality; that the
core or moral knowledge is essential theoretical, or an explicitly statable, highly
general and systematically unified type; and that this pure theoretical core of moral
knowledge is essentially action-guiding, so that when brought to bear on the
incidental "nonmoral" information about a situation at hand, it tells "the" agent what
to do (p. 53).\textsuperscript{138}

Yet, a strictly theoretical approach to responsibility, just like a strictly theoretical
approach to morality, misses much of the richness of human life. It fails to uncover the

\textsuperscript{138} Italics and quotation marks are Walker's, not mine.
diversity of responsibilities that constitute people’s everyday experiences. It fails to account for the interconnectedness between responsibility and moral identity. Indeed, who one is or wants to be for others will affect whom one feels responsible for and how this responsibility is enacted. Responsibility to others is part of a meaningful life. Just as feminist ethicists have called for the need for a relational approach to autonomy, relational responsibility provides another way of thinking through what it means to exist in relationship, to be interdependent and bound up with others. Practices of responsibility come with their own burdens and potential harms, but I concur with Lloyd when she writes responsibility in the context of interdependence and friendship “creates further possibilities of subjectivity and agency.” (Lloyd 2000: 118). Indeed, this study suggests that moral agency may be advanced through different manifestations of responsibility. This takes into account the potential for individual (and I suspect collective) action when people see themselves in relation to known as well as unknown others. Participants’ willingness to engage in research, for example, suggests a kind of relational citizenship. Their participation in research appeared to be far more than a social duty; rather it was expressive of the desire to provide social benefit.

At the same time, it is important to recognize not all responsibilities are voluntarily chosen. Further, as a concept, relational responsibility runs the risk of reinforcing stereotypical roles that may be harmful to certain people’s autonomy. Just because a decision or action is taken out of responsibility for others, does not always mean that it is autonomous because the factors that went into assuming that responsibility may be constructed out of oppressive norms. Feminist scholars have long shown how social “conditions of blameworthiness” (Benson 2000: 72) and responsibility reinforce social arrangements that oppress women. It may serve to constrain their autonomy. However, while I agree that
women/men assume and manage their responsibilities in socially and culturally shaped ways (and that some groups are burdened more than others), I am wary of an account of responsibility that is purely social and political. This too can be overly deterministic and fail to account for the richness of people’s experiences. Recognizing the social construction of responsibility and agency does not mean we have to accept who we are or are supposed to be. As well, it does not acknowledge (some) people’s ability to set a new course. As Britzman (1991) reminds us, just as culture shapes people in the course of depicting their own lives, people also construct culture. In examining how people respond to genetic technology and other kinds of medical interventions, we need to remain attentive to how people “define what is possible and desirable for themselves and others” (Simon and Dippo 1986: 196). At the same time, we should remain attentive to the structural forces that may advance, limit or constrain these possibilities. An acceptable approach to relational responsibility requires respect, concern and support for the well-being of all persons within relational structures.

Summary

In this chapter, I situated the study findings within a broader context by discussing the ideologies of genetic determinism, cancer survivorship and choice. I also drew together some of the key themes presented in the preceding chapters to illustrate how knowledge of genetic risk may affect the ways in which people think about themselves, as well as themselves in relation to others. In evoking the categories of the embodied, relational and social self I illustrated that the fluid boundaries between the self and others. I contributed to a growing body of philosophical and social science literature that shows how insubstantial western concepts of the ‘individuated’ self can be.
Philosophers have long written about moral responsibility as a normative concept, but little work has been done to examine what this actually looks like in practice. In applying the tools from ethnography, my aim has been to make visible the moral issues that arise when we start from people’s experiences of genetic testing for hereditary breast/ovarian cancer. Yet, this study has not taken ethnography to the next level: that is I have not situated genetic testing within the web of broader socio-economic and political influences that structure its use. These influences are going to continue to shape and re-shape how genetic testing is conducted. For example, I have not assessed the high cost of genetic testing, who profits and who benefits from this technology or the potential impact of commercialization. How do policy makers, health care providers and funders influence how genetic testing is used and understood? How do they contribute to both the practicalities and ideologies surrounding this technology? How does policy and economic interests affect the choices available to women from hereditary cancer families? These questions remain pivotal to broader discussions of genetic testing, but are beyond the scope of this thesis.

While this study focuses on the impact of genetic testing and hereditary cancer risk, I wish to emphasize that genetic testing evokes only one story of many that can be told about the self. For example, people’s perceptions of their embodied selves will be affected by other physical characteristics, abilities/disabilities, illnesses or concerns in addition to genetic risk. The relational self is influenced by connections, commitments and responsibilities to biological kin in a variety of manners as well as by relationships to friends, partners, colleagues and even neighbours. Clearly, a myriad of factors go into shaping whether or how

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139 Recall that British Columbia is the only province in Canada that has ceased testing because of Myriad’s threat of a patent suit. Therefore, individuals living in B.C. have different opportunities of access to genetic services than do those living in other provinces. This is an excellent example of how political and economic interests influence choices available for people, and in turn how a technology may be used and understood.
individuals view themselves as belonging to a particular social group. The assumption and negotiation of responsibility is an ongoing process that traverses many facets of social life. Genetic risk information, although very powerful and may affect the way people think about themselves and connections to others, is only one component of many that can affect a person's understanding of current and future self. At the same time, however, I do not wish to minimize the profound effect that personal and family experiences of breast/ovarian cancer have on people's lives. With this in mind, I move to the final chapter in which I summarize the key findings of this investigation and consider their practical relevance to clinical practice and research.
CHAPTER 9:
Towards Further Understanding
Of Genetic Technologies

If we had a keen vision and feeling of all ordinary human life, it would be like hearing the grass grow and the squirrel’s heart beat, and we would die of the roar which lies on the other side of silence.

---George Eliot, *Middlemarch*

Introduction

Genetic testing for hereditary breast/ovarian cancer creates the unique situation in which individuals may learn in advance whether they are at increased risk for developing the disease. While issues of privacy, confidentiality of information and discrimination remain a focus of ethical discussion, few studies have attempted to explore the influence of genetic information on people’s moral experiences or expressions of moral agency. Yet, I entered this study believing that attention to this is crucial if we are to engage in a more critical reflection of the moral impact and social effects of genetic testing for hereditary breast/ovarian cancer. This study has contributed towards those ends.

Guided by feminist ethnographic methods, this research offers a descriptive and critical analysis of how people view, interpret and live with genetic risk information in their everyday lives. It highlights the connections between personal and family history, relationships and knowledge claims, on the one hand, and constructions of risk perceptions and conceptions of self, on the other. It provides new insight into different ways of coming to know hereditary cancer. It adds to the body of knowledge about the implications of genetic testing on family connectedness, communication and relationships with others. It presents a conceptual framework for looking at how moral agency and understandings of self are affected by genetic information. It illuminates analyses of moral agency through concepts of
identity and self (embodied, relational and social self) in ways that have not been explored before. It also identifies ‘responsibility to others’ as a major facet of moral identity and understandings of self. The study also contributes new understandings about disclosure of genetic information and the gendering of responsibility. It makes visible how moral questions generated by genetic technology may shift and vary with life stage. The research adds to the paucity of information about the moral experiences and decision-making of those who elect not to be tested. In sum, this dissertation demonstrates that when genetic testing is examined contextually, it is a far more complicated matter than when viewed through a theoretical lens.

This chapter provides a summary of the research. I begin by highlighting the key themes presented in Chapters Five through Eight. I then turn to methodological reflections about the study. I discuss some of the strengths and limitations of the research design, study sample and analysis. Next, I draw on the analysis of the study data to provide recommendations for clinical practice and future research. I discuss the kinds of interventions needed to shift health care practices towards priorities identified by users of this technology, and to provide some recommendations on how best to support people with their concerns. As Anderson (1991) states so aptly, it is crucial the researcher must take the research beyond giving voice to the lived experience to using it to aid participants’ lives. One of my explicit intentions has been to create knowledge that may improve care for those undergoing testing in the future.

Summary of findings

The following provides a summary of the key themes that have arisen from the study. While I recognize these themes are constructions, I also believe they yield some important
insights about the moral and social impact of genetic testing for hereditary breast/ovarian cancer.

- Knowledge of hereditary cancer is obtained within the context of the individuals’ story as well as within the family and society’s broader stories. Participants discussed coming to know cancer in two ways: embodied and empathetic knowing. Embodied knowing refers to women’s actual experiences with breast cancer, chemotherapy, radiation treatment and surgery. It is knowledge gained by living with the disease, including ongoing physical and emotional changes. Empathetic knowing, on the other hand, refers to knowledge that is acquired by living with or having close contact with others who have a particular illness. It is affected by the kind and amount of shared experiences with a relative(s), the variability of a relative’s illness trajectory, the extent of suffering witnessed and the sheer number of family members who had died. Because of the nature of hereditary disease, many participants knew breast/ovarian cancer in both ways. Embodied experiences, as well as the experiences of kin, were integrated into knowledge claims about familial cancer. This kind of experiential knowledge plays a powerful role in decision-making about genetic testing.

- The opportunity to be tested and the information gained from genetic testing intersect with three aspects of the moral self: the embodied self, the relational self and the social self. These elements refer respectively to the manner in which people viewed genetic testing when thinking about their physical selves, their families’ health and well-being and their general relationship to unknown others. For example, while participants’ decisions to seek testing reflected practical concerns about their health, the self in relation to others was also instrumental in making these decisions. Some women believed testing could give their daughters, sisters and other female relatives information that would be useful for them. Others, referring to their own experiences with breast cancer, hoped that genetic information would allow family members greater control over the disease. Many participants also wished to be tested in order to provide information that might benefit medical research and society more broadly.

- Choice did not appear to be ‘autonomous’ in an individualistic sense, but existed along a continuum of self-care and concern for others. Choices around genetic testing were influenced by many intersecting factors including context, family history, empathetic and embodied knowledge, relational commitments and responsibility to others. Choice was also influenced by dominant social discourses, which define genetic determinism, cancer survivability and femininity in certain ways. While most participants talked about genetic testing as providing choice, a few spoke about their relatives’ decision to undergo genetic testing as compromising their right not to know and accordingly their autonomy to make choices around this matter.
The discovery of a genetic mutation appeared to mark a crossing from a theoretical or possible risk to an actual threat. The majority of participants used this information for decision-making and health care management of their embodied risk. It allowed them to take action that changed their self-perception from an uncertain self to a safe self, as well as to provide information for others. A few, however, were affected negatively by information about their carrier status and viewed their bodies as highly risky. Knowledge of their mutation status threatened not only their physical lives, but also their social roles as partner/parent and accordingly their sense of agency. Another few responded to the information with ambivalence.

Genetic inheritance elicited both a sense of fatalism (genetic determinism) and a sense of control. Most mutation carriers interpreted their results as meaning they were destined to get cancer, but at the same time they thought the information was advantageous in that it would allow them to be more vigilant about their health. The weight participants gave to either of these interpretations (fatalism versus control) varied with individual experience, life context and family history. People's responses to genetic information were further influenced by factors such as socio-economic status, ethnicity, age and geographic location. Examination of 'life stage' showed how genetic information raises different moral questions for young adult women. In particular, reproductive decision-making became more complex for younger adult women who knew they carried a mutation.

Genetic information was viewed as information about the family and as such, most participants perceived that they had an obligation to make this information available to their kin. Sharing of information was extensive within this realm. Women, however, were more likely than men to share information outside the nuclear family with extended family and friends and others members of the community.

Building on concepts of a relational self, 'responsibility to others' proves to be a major facet of moral identity and understandings of self. Just like autonomy and integrity, responsibility is a value that intersects with the formation, negotiation and continual transformation of self. Responsibility to others should not be seen as just an obligation, but a complex expression of self-governance through which people enact their moral agency. Morality is deeply rooted in the responsibilities people assume. Responsibility to others underscored participants' reasons for getting tested (or not), what they did with the information and to whom they disclosed their test results. Within the context of genetic testing, responsibility to others may not be limited to the present or to known people. Responsibility to others may also include actions taken for future generations as well as society in general.

Relational responsibility provides another way of thinking through what it means to exist in relationship, to be interdependent and bound up with others. Attention to this construct also reinforces the importance of understanding the complex
social nature of genetic testing, including how responsibility is shaped by broader social and cultural worldviews. This concept, although particularly relevant to genetic testing, may be useful for assessing the moral and social implications of other medical technologies as well.

- Genetic testing for hereditary breast/ovarian cancer has the potential to influence a person’s sense of family or cultural identity. This may occur in two ways. In discovering new family or extended kinship through genetic testing, the latter has the potential to change the way people think about themselves or their self-identity in relation to their family and biological kinship. Secondly, some BRCA mutations are linked to specific ethnic and founder populations. Identification of specific ethnic mutation may cause some people to reconsider or question their ethnic and cultural identity.

Methodological reflections

Throughout this study, I have emphasized the importance of understanding genetic testing for breast cancer from the perspectives of women and their families. Ethnography provides us with a point of entry. Through constructed narration it gives us a glimpse into the contradictory realities of genetic testing. An attentiveness to language, stories and participants’ accounts provides insight into the choices or moral dilemmas faced by people with hereditary disease. But an ethnographic study makes for a cautious study. As Britzman (1991) reminds us, “The re-telling of another’s story is always a partial telling, bound not only by one’s perspectives, but also by the exigencies of what can and cannot be told. Narratives of lived experience -- the story, or what is told, and the discourse, or what it is that structures how a story is told -- are always selective, partial and in tension” (p. 13).

The data for this study were derived from individual interviews and field observations collected from 1998 to 2001. Interviews with 53 participants from 14 families were conducted in two main phases: 29 in 1998 and 20 in 1999. Four additional interviews (two in 2000 and two in 2001) were held the following years. I also had the opportunity to conduct second interviews with six participants whom I met with during the first phase. Working
closely with genetic counsellors and geneticists at the Hereditary Cancer Program, I undertook approximately 50 hours of fieldwork as an observer in genetic counselling sessions. In addition, I attended monthly clinical review and steering meetings of the Hereditary Cancer Program at the BCCA. I began attending these meetings in September 1997 and continue today. This research focused primarily on the accounts of at-risk individuals who underwent testing (n=39) and those who were eligible but declined testing (n=6). I also had the opportunity to interview 4 spouses (2 men, 2 women) and a son (n=1) of those who underwent testing, as well as three women (1 mother and 2 daughters) who were awaiting test results.

Before discussing the limitations of the research, I wish to briefly comment on the writing process itself. This dissertation presents the study as a linear progression. In the written form, the chapters seem framed and final in their completion. This greatly masks, however, the disorder that plagued the work. In particular, I struggled with the analysis; allowing themes to ‘emerge’ from the vast quantity of data proved difficult. As I read and re-read the interviews, I felt overwhelmed by the diversity of participants’ experiences. Each individual’s account was so unique; so many things shaped, influenced or could affect what was said. To look for themes or theoretical categorization seemed also incompatible with what I was told. Yet, as a researcher I recognized that my analysis began with the first question I voiced. It was manifest as I collected the data and is manifest here. But as certain themes are highlighted over others, it is important to recognize this analysis represents a partial understanding. It is limited by the fact that I am one researcher conducting work in a specific practice setting with a particular group of people. Further just as the participants in this study, I cannot claim to acquire or represent knowledge neutrally. I also bring ideas to
this work that are shaped by my experiences, knowledges and various locations. I too write (and speak) with a history.

A number of other limitations are inherent to this research. For one, information about genetic susceptibility and genetic risk for hereditary breast/ovarian cancer is constantly changing. The BC Cancer Agency's Hereditary Cancer Program has been modified several times over the past six years as new findings suggested different strategies. I found it exceedingly difficult to keep up with the burgeoning field of genetic science, as the number of references in Chapter Two attest to. Further, much of this knowledge is tentative. Genetic testing and counselling practices are based on current understandings, but change in response to new scientific developments and ongoing professional experience with the technology.

Secondly, genetic testing raises questions about risk that for many people are new and may be difficult to articulate. Research (both qualitative and quantitative) demands that we focus on issues that are measurable and can be articulated. Yet, the things we often care most about are not easily measurable and may even defy words. It is important to recognize that language may fail to adequately portray the concerns people have. Likewise, it is important to recognize that some people might not give genetic testing or the development of new genetic technologies much thought. Their viewpoints are likely to be under-represented here, as the study participants represented a highly motivated group of people. Recall that only about one-third of those who receive genetic counselling for hereditary breast/ovarian cancer actually have the test. With the exception of those who declined testing or were spouses/partners of those eligible for testing, study participants comprised this group. Their family histories were striking in the number of people affected by cancer; and thus they may place more value on genetic testing than those who have significant, but less extensive family
cancer backgrounds. As well, many of the participants I met had already received treatment for breast/ovarian cancer or cared for others with cancer. In light of familiarity and involvement with the medical system, genetic testing—although useful—may be viewed as having similar utility to medical tests in general.\footnote{140}

Thirdly, this type of study cannot account for the deeper conflicts, ambivalences, and practical details of everyday life that will also affect how this information is understood (MacKay 2001). Similarly, it is impossible to account for how individual personality traits may influence responses to genetic testing. In other words, how people deal with genetic information may parallel how they deal with other aspects of their life; it is not necessarily unique to information gained from genetic testing per se. Those who tend to be anxious about things in general (for example, the ‘worried well’) may also be excessively anxious about what genetic knowledge implies. A study like this cannot account for and may even mask how individual emotional and/or personality traits affect receipt of genetic information or how certain family members take on, acquire or are assigned specific roles by other family members.

Fourthly, although every effort was made to include people from different ethno-cultural backgrounds, the study population comprised people who were of Euro-Caucasian descent. This lack of diversity reflects the background of those who have sought services at the HCP to date. Yet this observation does raise important clinical questions about access and the delivery of information about testing programs to different ethno-cultural communities. At the research level, questions about whether or how ethno-cultural differences intersect with understandings of genetic risk remain.

\footnote{140} I thank Dr. Nancy Waxler-Morrison for bringing my attention to this point.
Finally, this analysis is limited by the fact that, with the exception of a few participants, it captures people's experiences at one point in time. Yet, people's lives are not static but ongoing. The self may move through various moral territories -- embracing, rejecting, modifying, even abdicating responsibility -- as genetic information is interpreted and acted upon over time. Families, relationships and moral ideas shift and are revised through interaction and negotiation with each other (Walker, 1998). Further, people's interpretation and responses to genetic information may shift as new knowledge about the medical implications of this test is gained. They are also likely to shift as political decisions make access to testing easier or more difficult. (Recall that due to the threat of a patent lawsuit by Myriad, the B.C. government ordered the BCCA to cease genetic testing for hereditary breast/ovarian cancer in July 2001). Ethnography, through constructed narration, can give us a glimpse into some of the concerns faced by those undergoing genetic testing. But this should not be considered the whole story. Personal meanings shift and change as other contexts, other voices and other experiences are taken into account or ignored. Notions of, and reactions to, genetic information may vary over time. If anything, an ethnographic approach should remind us that genetic testing is just one point in a life-long narrative of moral deliberation and thought.

Clinical implications

While this study has contributed to ethical analysis of genetic testing, in keeping with other feminist theorists I strongly believe that the researcher must take her study beyond giving voice to the lived experience to using it to aid participants' lives (Anderson 1991). The discussion that follows is grounded in my commitment to use this research to address issues and concerns identified by users of this technology. Here, I discuss the clinical
implications of the study findings in five areas: (1) Communication of genetic information (2) Responsibility and informed consent; (3) Disclosure of genetic information; (4) Coercion and (5) Counselling men for BRCA mutations. I propose some specific strategies that I believe will improve clinical practice (and thus provide better care for patients) as well as suggest some recommendations that may aid decision-making regarding this technology.

**Experiential knowledge and information exchange**

I have argued that experiential knowledge has a profound effect on illness representation, decision-making as well as risk perception. Thus, while the detection of a BRCA1/2 mutation may present similar medical risk, women/men have different beliefs about their personal susceptibility to cancer based on their subjective experiences. Indeed, research repeatedly shows that inaccurate and/or exaggerated perceptions of risk persist even after genetic counselling (Lloyd, Watson et al. 1996; Cull, Anderson et al. 1999; Elwood 1999; Rees, Fry et al. 2001). Clearly, this is an issue that demands attention.

Constructivism has evolved as the core of adult education and learning. At the heart of this epistemology lies the belief that “knowledge does not reflect an ‘objective’ ontological reality exclusively, but an ordering and organization of a world constituted by our own experience” (von Glaserfeld 1984: 24). An essential goal of counselling is to provide people with information so that they can make decisions based on their values, needs and beliefs. Yet, genetic counselling – like much of medical education -- remains embedded in the conduit metaphor of learning. Here, learning is conceptualized as the transmission of knowledge from a cultural authority (expert, curriculum, textbook, media) to the learner (Roth and Roychoudhury 1994). While, genetic specialists (geneticists, genetic counsellors and nurse educators) recognize that people’s interpretation of genetic information will be
influenced by their backgrounds, constructivism as an approach to information exchange is not fully employed. From my perspective, genetic information is presented as a series of facts and risk probabilities. Patients are expected to accept this information and treat it as real. Yet, findings from this study suggest that counselling practices might benefit from an expanded exploration of their client’s experience with cancer based on constructivist principles. This means that in addition to taking family history, genetic counsellors need to engage in a more detailed discussion with clients about their experiential knowledge. (This kind of discussion would include topics such as: How do you think about cancer given your family history? Do you see breast/ovarian cancer as a disease from which one survives? How do you see cancer in terms of yourself?). An exploration of individual experience, as well as sensitivity to different ways of knowing, promises to aid counsellors in assessing how people from hereditary cancer families think about and internalize genetic risk information. The research shows, for example, that women who come from families with an extended history of cancer and/or who have had personal experience of caring for family members through their terminal illness, tended to interpret genetic information as highly deterministic. Knowledge of this and other experiences promise to help counsellors better understand their client’s position. It may also suggest new strategies for the communication of risk information that are better tailored to the client’s needs.

As well, awareness of the impact of genetic information on the embodied self (aware, safe, risky and uncertain self) offers to aid counsellors in evaluating the meanings people give to their tests results. It can help serve to clarify why some people tend to cope better with genetic test results than others. Especially important, it may help counsellors identify individuals who are disturbed by this information and require further psychosocial
counselling and support. Conversely, an understanding that most people from hereditary
cancer families view genetic information as valuable (and enhancing the opportunity for self-
awareness and safety) suggests new avenues for delivery of test results. As detailed in
Chapter 2, the protocol for genetic counselling, testing and delivery of test results has been
patterned after the Huntington Disease protocol. Clients are required to return to the clinic for
receipt of a definitive test result because of concern about the psychosocial consequences. (In
the event of an indeterminate test result, the client is informed by telephone). Yet,
participants frequently told me that they found this requirement burdensome and
unnecessary. Those who came from areas outside the lower Mainland faced additional travel
and financial burdens as well. Thus, clarification of the client’s perspectives on the utility of
genetic information, and how it may impact themselves, offers a starting point for
counsellors to consider with patients about how best to deliver the test results.

Responsibility and informed consent

Genetic testing for hereditary breast/ovarian cancer is enacted within a discursive
practice (medical, ethical and legal) that gives primacy to individualistic models of
autonomy, rational decision-making and choice. Yet, this study has shown that autonomy is
not the primary principle through which health care decisions are framed. The values that
dominated research participants’ thoughts and responses to genetic testing concerned
relationships. In Keller’s words, they emphasize “connection and relatedness” (1985: 173)
and suggest a more contextual approach to ethics based on caring relationships of involved
persons (Sherwin 1992; Baier 1995; Tong 1997). In describing experiences around genetic
testing, participants articulated such values as responsibility, caring, fairness, and respect.
Also embedded in some accounts was a strong sense of altruism. Although some spoke of
individual choice, the language of responsibility coexisted and often prevailed over that of individuality or individual rights. Genetic testing was understood within ongoing relationships, which in turn had different meanings and commitments for various participants.

What does this mean for clinical practice? As with any medical test, individuals are encouraged to exercise personal autonomy in deciding whether or not they wish to pursue genetic testing. From a clinical standpoint, autonomy is supported through standardized protocols that emphasize genetic counselling and informed consent (Burgess, Knoppers et al. 1999). In pre-test counselling, individuals discuss with genetic counsellors the possible benefits and harms of receiving genetic information. Patients must evaluate whether the risks are worth taking based on their own values and notions of welfare. Similarly, people's entitlement to privacy ensures that they are seen as knowing best with whom, when, and how to share this information.

Yet, similar to experiential knowledge, attention to relational activities and responsibilities offers to enhance the process of informed consent. This study indicates that a practice that attends solely to information delivery may miss aspects of that individual's life that are relevant to her or his decision-making. Recognizing that choice regarding testing and sharing of genetic information is shaped by commitments and responsibilities to others, for example, suggests that genetic counselling should be tailored to take into account these kinds of responsibilities. It suggests that providers shift the discussion away from information delivery per se to how genetic information can be used to support people's personal and relational activities. Linking self-determination with relational responsibilities promises to help identify information that is relevant to the evaluation of the benefits/harms
of genetic testing on patients, their families and their communities. This, in turn promises to enhance informed decision-making and augment patients' abilities to exercise autonomous choice.

Disclosure of genetic information

The question of "who owns genetic information" has been a major focus of ethical inquiry. Applied to predictive testing, several recent critiques suggest that persons with a genetic disorder have a moral duty to disclose that information to other family members (Jonsen 1994; Rhodes 1998; Sommerville and English 1999; Weijer 2000). The justification for this obligation is that genetic information belongs not only to the tested individual, but to members of a biological kinship for whom that information may have medical or reproductive implications. Attention to experience-based responsibilities, however, serves as a valuable counter-point to more abstract discussions of role-based responsibilities concerning disclosure.

For one, it suggests that the moral duty to disclose genetic information is something that cannot be abstractly assigned. Rather this is a duty that acquires meaning, is lived out and therefore can be evaluated only in the life context and history of particular individuals. As an abstract rule, the duty to disclose inadequately considers the costs and benefits of such a task. Secondly, the research suggests that a "duty to disclose" may be an inappropriate orientation in most counselling relationships since family members tend to readily disclose to each other. (In fact, I would argue that the duty to disclose is more problematic to philosophers and ethicists than it is to those who have genetic test results. If participants in this study are reflective of those more broadly, carriers tend to readily disclose). Thirdly, it shows that the duty to disseminate genetic risk information is attached to a gendering of
responsibility. Although this is part of a social practice that already assigns women disproportionate responsibility for family care, justice would require that the burdens as well the benefits of disclosure be distributed fairly. This study indicates that they are not.

This finding has practical implications for geneticists, genetic counsellors, and other health care providers who evaluate and counsel patients for genetic risk. Counsellors need to be aware that assigning or suggesting that there is even some responsibility to discuss inherited risk may be experienced differently by women compared to men (as groups). Further, through “non-directive” counselling, they may unintentionally or implicitly reinforce this imbalance of duty. To avoid bias, genetic counselling might be better nuanced so that it takes into account these gender differences. Apportioning the task of disclosure fairly may be possible if the issue is open to discussion. For instance, men might need more explicit description of who could benefit from this knowledge. They might be counselled about the value of communicating this information to a broader range of family members, whereas for women this discussion might be unnecessary or add to the sense of responsibility they already feel. Alternatively, recognizing that many women readily share this information with others, genetic counsellors might offer their female (as well as male) clients some additional support or assistance in this task. A counsellor who provides written materials describing the implications of a genetic diagnosis, for example, may aid their clients to inform other kinship members and thus assist them in fulfilling their responsibilities to others.

At the same time, it is important to recognize there are situations where clients may not act responsibly. They may choose not to share information that may be relevant to the health care of other family members, and questions regarding the responsibility of particular clients to others (or physician to patient) may need to be asked and the duty to warn
considered (Burgess and d'Agincourt-Canning 2001). Conversely, patients may take on too much responsibility. They may be self-sacrificing and seek genetic testing to fulfill obligations that are unrealistic or oppressive to them. They may make unreasonable choices based on this and may need to be warned of this fact. These kinds of controversies cannot be resolved in the abstract, however, but require attention to the details of each person's experience and life context.

Coercion

Relational responsibility provides a space where people are active moral agents in relation to the self and the others. Yet also relevant to genetic counselling is the fact that feelings of genetic responsibility may lead to the coercion of others. In an attempt to do good, those who have experienced the trauma of breast/ovarian cancer may feel a greater need to convince daughters and other family members to be tested whether the latter want this information or not. Thus, important to genetic counselling is the recognition that coercion does occur, especially between mothers afflicted with cancer and daughters. This implies that providers should be prepared to counsel clients about the negative effects of pressuring family members to be tested. Such a discussion would emphasize respect for individual choice, the emotional risk associated with receiving information for which one is not prepared, as well as highlight how genetic information poses different issues for people at different life stages. Parents need to be aware that while genetic information may be seen as an immediate health benefit for a woman in her 40s, it raises different life concerns for a younger adult in her twenties. Some of these may be disturbing or even life-limiting and should be discussed in depth. Counsellors may also advise clients who express concern about daughters or other relatives not showing any interest in testing, that while young adults may
not see genetic information as immediately useful to them, their perception of its utility may change over time.

Counselling for men

This study shows that genetic testing for the BRCA1/2 mutation may affect men more than might be suspected. Although not worried about getting breast cancer per se, men who were found to be BRCA mutation carriers reported concern about being at risk for other types of cancer. The lack of long-term studies about whether or how this mutation may potentially affect men also contributed to their uncertainty. Genetic counsellors typically focus on women’s concerns because they are most at risk for developing cancers related to the BRCA1/2 mutation. For example, unlike female carriers, men do not receive follow-up calls from genetic counsellors if they test positive for a BRCA mutation. Yet, this study implies that counsellors should be aware that some men do attribute some significance to their positive mutation status and might benefit from a follow-up phone call. At the very least, counsellors could recommend that if a male carrier is concerned about his positive findings, he should inform his family physician and perhaps establish a screening protocol (i.e. for prostate cancer). Men should also be aware that psychosocial support is available if they experience emotional guilt or anxiety over being the source of their children’s mutations.

Directions for Future Research

This study has broadened the understanding of the impact of new genetic technologies by integrating ethical analysis with ethnographic research. Like other researchers undertaking ethnographic studies, however, I am left with numerous unanswered
questions. These questions have relevance for both clinical practice and ethical analysis, as well as suggest directions for further research. It is to the latter I now turn.

Life Stage

A salient finding of this study is that genetic information is interpreted differently, and raises different moral questions and choices according to life stage. Life stage is not just an empirical reflection of age, but it also incorporates normative assumptions and social expectations about how we should look, behave and how we ought to live our lives (Overall 2002). Traditional ethical analyses, as well as psychological studies, have failed to recognize this feature in examining the impact of genetic testing. Rather, most arguments or queries are based on the presupposition of a standard, generic human self.

Yet, findings from this study indicate an urgent need to examine the implications of genetic testing with respect to life stage. Although I am mindful that experiences around genetic testing are shaped by a host of factors, we need to examine more closely the potential for harm in adolescents and younger adults. Is there a tendency for the lives of younger women to be more affected by the foreshadowing of genetic information than women who are older and perhaps more settled? Because most young adult women do not view prophylactic surgery as an immediate option, do they become distressed about their embodied risk? In a similar vein, longitudinal studies are needed to fully understand the long-term consequences of knowing one is at genetic risk. Does it have the potential to affect notions of self, agency and capacity for intimacy and relationships with others? Testing of younger adults also bring others question to bear. Does frequent and intense screening transform a woman’s understandings of their risk? With this kind of screening, do young adult women begin to view their bodies as more ‘risky’ or do they see screening as ensuring
their safety? Anecdotal evidence (personal conversation with Mary McCullum, nurse educator for the HCP program) suggests that for some women, the former may be true. She told me that one woman in their high risk screening program elected to have prophylactic surgery because the intensive screening made her quite distraught; at each appointment, she was terrified that a cancer would be found. Although it would be irresponsible on my part to ‘analyze’ this account, it does suggest another area for further research. Crucial to gauging the benefits of surveillance is the question: Does intense surveillance change perceptions of risk by making it more salient to the individual? Clearly, such studies are needed to better understand the impact of genetic testing and therapeutic options on younger age groups. Further, follow-up with larger studies are needed to assess whether and how younger women make reproduction decisions based on genetic test results. As well, does knowledge of genetic risk impact the way they feel about the birth of their child and associated activities such as breast-feeding? Anecdotal findings from this study suggest that it may. Clearly, this kind of information is essential for gauging the benefits and harms of genetic testing and for developing counselling approaches that are targeted to patients’ needs.

While the previous discussion has focused on younger adults, similar studies using “life stage” as a unit of analysis are also needed to better understand the impact of genetic testing on women in their middle and older years. Not only would such studies extend the understanding of the nature of genetic information, but they might also suggest ways to enhance therapeutic management and improve communication of risk information.

Disclosure of genetic information

Genetic testing for hereditary disease is associated with a responsibility to disclose test information that does not exist with other medical tests. Indeed, this study showed that
most people view genetic information as beneficial to the family and disclosure of
information is extensive within this realm. Many held the view that family members had a
right to genetic information, especially if it might improve another’s welfare. Yet needed
here is an in-depth exploration of the consequences of such disclosure. Specifically do people
welcome getting medical information, which they have not sought themselves? Ethical
arguments about the duty to disclose are based on the assumption that knowledge about
genetic risk is beneficial; that it is better to know than to not know. Indeed, participants’
reasons for disclosure embraced this discourse, as well as drew frequently on the cultural
ideology that knowledge is power. Yet, further empirical work is required to assess how
women, as well as men, respond to getting unsolicited information about their risk for
carrying a genetic condition. Is this information valued or is disclosure of genetic information
seen as invasive? Put another way, how much are we interfering with others and in fact
overriding their privacy and right not to know their genetic status because of a perceived duty
to disclose?

Social identity

Chapter 8 provided a discussion of how genetic information can impact people’s
social identity in two ways: kinship identity (where one fits into the family structure and
family line) and social identity (connection to a specific religious, ethnic, or social group).
Individuals may learn about family they had never known through genetic testing, and
likewise discover for the first time they share biological/genetic traits associated with a
specific social group. Both areas require further investigation in order to address possible
harm or tensions that might arise from this knowledge. As previously mentioned, BRCA
mutations comprise a range of genetic alterations, some of which are linked to ethnic and
geographically-based founder populations (Ashkenazi Jewish, Quebecois, Icelandic, Scottish, Polish etc.). How these genetic mutations are perceived, negotiated, managed and used within the context of inheritance and ethnic or cultural identity is open to question. This may be a nonexistent issue or one of scale, but research in this area is vital to enhance understanding of the personal, social and political dimensions of genetic testing. It is also needed at a broader level to guard against the possibility of stigmatization or discrimination based on genetic characteristics. Likewise, this study showed that genetic testing frequently affects the ways in which people come to know and act upon their biological connections to others. Further research is needed to examine the potential harms and benefits that can arise from this activity. This type of information would also help genetic counsellors better support clients who are in such a situation, or who seek their advice about contacting distant family members.

Concluding thoughts

This study has sought to extend ethical analysis by exploring what ethnography can bring to certain issues. All too many debates in medical ethics deal in abstractions, or are removed from those most intimately involved in the issues such as patients, family or caregivers (Conrad 1994). It is important to broaden ethical analysis so that its concepts and methods include the voices and experiences of the people it studies. While normative evaluation is important, we cannot assess the moral impact of genetic testing without looking at its application and influence in people’s everyday lives. In doing so, this dissertation has aimed to foster a deeper discussion of the social, philosophical and ethical issues raised by genetic testing for hereditary breast/ovarian cancer. It seeks to help build a bioethics that is more sensitive to the values, commitments and concerns of those who seek genetic testing (or
not). Yet, it has also left open many questions. Indeed, the ethical quandaries created by genetic testing will never yield a single answer, but require an ongoing and active search for a balance between people's lived morality and science. This enormous task brings me back to the wisdom of the Hmong (Fadiman, 1997): 'No event occurs in isolation and you can miss a lot by sticking to the point.'
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APPENDIX 1

HCP Criteria for Referral and Genetic Testing
Referrals to the Hereditary Cancer Program: Criteria for Genetic Risk Assessment

To ensure that all patients who might benefit from detailed assessment of their family's cancer history receive the same standard of care, and to make the best possible use of our current resources, we request that you follow the referral process described below. The following page provides some background about the Hereditary Cancer Program (HCP) and the genetic counselling process. Please note that the criteria are reviewed regularly and may be revised in the future.

Genetic risk assessment may be appropriate if a family history meets one of the following criteria:

- a woman with breast cancer diagnosed at age 35 or younger OR
- a woman with ovarian cancer diagnosed at age 50 or younger OR
- an Ashkenazi Jewish woman with breast or ovarian cancer diagnosed at any age OR
- a man or woman with colon cancer diagnosed at age 50 or younger OR
- a blood relative with a confirmed mutation of a cancer susceptibility gene (e.g. BRCA1, BRCA2)

OR if a family history includes any two of the following on the same side of the family:

- cancer in 2 or more closely related family members (parents, siblings, children, grandparents, aunts, uncles)
- cancers at an earlier age than expected in the general population (e.g. breast cancer before menopause or colon cancer before age 50)
- multiple primary cancers in 1 individual
- cancers associated with known hereditary syndromes (e.g. breast/ovary, colon/uterus)
- male breast cancer

How To Make A Referral For Genetic Risk Assessment

A referral must come through a physician. From anywhere in BC, a referral is made by:

- returning the Referral Form (completed by the physician) AND the Family History Form (completed by the patient) OR
- calling (604) 877-6050 to request a referral to the Hereditary Cancer Program -> the forms will be sent to you
- referral forms should be available for printing from the BCCA website: www.bccancer.bc.ca Follow the links to Info for Health Care Professionals -> Cancer Management Guidelines -> HCP
APPENDIX 2

Grant Information and Objectives

GRANT INFORMATION FORM

Revised: 1997 June 05

1. PRINCIPAL INVESTIGATOR'S SURNAME, GIVENAME(S): BURGESS • Michael MacDonald

2. ACADEMIC RANK: Associate Professor

3. UBC FACULTY / DEPARTMENT: Centre for Applied Ethics

Grad Studies/Medicine Medical Genetics

4. E-MAIL ADDRESS: mburgess@ethics.ubc.ca

5. PHONE NUMBER: 6. FAX NUMBER: 822-0535 822-6627

7. PROJECT PERIOD (YY/MM/DD): 1997 September 01 to 2000 August 31

8. SOURCE OF FUNDS

Canadian Breast Cancer Foundation; Huntington Society of Canada; Earl & Jennie Lohn Foundation.

9. INDICATE THE INSTITUTION(S) WHERE THE RESEARCH IS BEING CARRIED OUT:

BCCAMPUS 0 VHHSC 0 SPH 0 BCWH 0 BCCH [X] BCCA 0 OTHER: at-home interviews

10. TITLE OF PROJECT:

Ethical and Moral Dimensions of Genetic Risk: Huntington Disease and Breast/Ovarian Cancer Experiences

11. ABSTRACT OF PROJECT:

This research evaluates at-risk individuals' and families' experiences of predictive testing in Huntington Disease in order to develop and apply new insights helpful to understanding the similarities with and differences from susceptibility testing for breast and ovarian cancer. Taking a participant-oriented rather than clinical perspective, this research stresses the importance of understanding in participants' terms the most salient ethical issues and how these issues present an alternative to a more clinically oriented approach. Utilizing individual and group interviews with families at risk for Huntington Disease and breast/ovarian cancer, we will identify processes through which at-risk persons and their families recognize and contend with salient moral issues. Bioethics has assisted clinicians to recognize their responsibilities by helping them to understand thoroughly the moral issues involved. Ethical analysis of participants' and families' moral issues will provide those involved with the means to understand and articulate the issues most central to their own family and social life. As such the research will be helpful to a range of people in the Huntington Disease and breast/ovarian cancer community and will enhance clinicians' and bioethicists' understandings of the day-to-day dilemmas which occur outside of, as well as within, the clinical context. Existing protocols for offering genetic testing and counselling, as well as their policy-related implications, will then be evaluated for sensitivity to the experiences of at-risk persons and their families.
Objectives

1. Describe the moral experiences associated with genetic testing for Huntington Disease and BRCA 1/2 from the perspectives of participants and their family members, and that of persons in at-risk families who are not counselled or tested.

2. Develop a comparative social and ethical analysis of the moral issues of predictive and susceptibility testing based on ethnographic data and perspectives.

3. Describe the effects of genetic testing for BRCA 1/2 on self-reports of utilization of interventions, and risk modifying and monitoring behaviour.
APPENDIX 3

Patient Information & Informed Consent Form
PATIENT INFORMATION AND CONSENT FORM

ETHICAL AND MORAL DIMENSIONS OF GENETIC RISK:
BREAST CANCER

INVESTIGATORS:
Michael M. Burgess, Ph.D.
Chair of Biomedical Ethics

Doug Horsman, Ph.D.
Dir., Hereditary Cancer Pgm

Lori d'Agincourt-Canning
Ph.D. Student
Interdisciplinary Studies

For more information, or to arrange participation, please contact Lori d'Agincourt-Canning at 921-9408.

PURPOSE
The purpose of this project is to describe how the availability and use of genetic testing affects the relationships and values of persons from families with genetic risks for breast cancer. We have two objectives. First, we want to understand what families at risk for genetic disease believe is of greatest importance when considering genetic risk in their lives. Our second goal is to understand how the availability of a genetic test or receipt of a test result or diagnosis might affect these values. It is crucial to a good understanding of these issues that family members who do not want anything to do with testing or genetic counselling also give us their opinions. The result of the project will be descriptions of what we think participants have told us are important moral values for them, and how genetic testing might affect the participants, their families, and their values.

PROCEDURES
In this study we want to understand what is important to members of families who may be at risk for breast cancer, including family members who are not at risk themselves. Information about familial risk and genetic risk for breast and ovarian cancer is available through the BC Cancer Agency’s Hereditary Cancer Program (877-6000; extension 2325). Since we want to interview people who have different experiences with breast cancer, whether their own disease and risk or that of a family member, we will not provide information about familial and genetic risk of breast cancer.

We are asking you to consider participating because either you or the family member who gave you this form has received genetic counselling. If you agree to participate in this research, we ask that you contact Lori d’Agincourt (study co-ordinator and interviewer) to discuss the interview and arrange a mutually convenient time and place. If you have met Lori, she will be calling you. The interview will require about 90 minutes. Lori will suggest that the interview take place in your home, but it is possible to work out a different location. In the interview, Lori will ask you to describe what is important to you, and about topics that others find important, when considering risk of breast cancer. Lori will send you a list of
Whether or not you participate in this project cannot affect your health care in any way. You will be given a copy of this “Patient Information and Consent Form” to keep for your records when you sign the consent form at the beginning of the interview.

Your signature here indicates that you have had the study explained, read this consent form, had any questions answered to your satisfaction, and agree to participate in the interviews described above.

Name (printed)

Signature

Date signed

Name of Witness

Signature of Witness

Date signed
APPENDIX 4

Interviews: Topics for Discussion

1. Can you tell me a little bit about yourself: where you grew up, where you live now, your work and family?

2. Have you or any of your family members had breast/ovarian cancer or other kinds of cancer? What are your experiences with the disease?

3. How much do you think about breast/ovarian cancer?

4. What prompted you to seek genetic testing for breast/ovarian cancer susceptibility? What is important to you in getting this test?

5. Can you describe what happened when you went for genetic testing?

6. What has been the impact of having this information in your life? Has it changed the way you view yourself, your future or your relationships with others?

7. Have you shared this information with anyone?
APPENDIX 5

Interview Segments on Prophylactic Mastectomy
Comments from a Few Participants

“We had talked about the double mastectomy and I had said that I was going to have that... the thing I knew I couldn't do was come home with no breasts. I couldn't do it. My friend, another breast cancer survivor at school, 12 years now, says, "Mastectomy scars are a beautiful thing". Well sorry, I don't think so, you know, and I had seen my mother's and I was just grossed out and disgusted. I have lots of scars on my body from other things. I DID NOT WANT THAT SCAR. I just/thought if I come home/you're going to think I am a basket case/ if I come home with nothing I am going to go mad. I am going to look at myself in the mirror and, I can't do it, I just can't do it. It's not even vanity, and it, maybe it's denial, you know, it's just I couldn't do it.” (Affected mutation carrier)

“I've been told that I'll go through a grieving period. I'm not sure when. Haven't had any chance. Um, had the surgery [prophylactic mastectomy and oophorectomy] at the beginning for Feb, my dad died [almost three weeks later], and my sister was diagnosed with ovarian cancer the day after that, and she had to go in for surgery and she's been going through chemo ever since then. And then [another sister] was diagnosed with the gene, and, I mean, and then [my daughter] was diagnosed with it. But that, those things, they weren't like traumatic in my life, but everything, I don't/ haven't had time to mope about this. Or if I did, maybe I didn't realize I was about this. Maybe I was grieving without realizing it. So, but I haven't felt any great loss in my life. Um, I keep telling my husband to play with them and see if they still feel the same. (laughing) He says can you feel anything? No I can't feel anything yet, push harder. (laughing) But I, I haven't had any, um, grief over losing them. I suppose it'll hit me maybe one day, but right now it doesn't. Not at all.” (Unaffected mutation carrier)

“It's not important to me. It's like, I am not worried about that, it's not something that I am second-guessing. I am totally scared witless about having, you know, both breasts removed, just because it is another big surgery and I'm so tired of hospitals and, I mean, once you go through all this [breast cancer], you just, you just don't want to go back there, you know.” (Affected mutation carrier)

“Most people I would say have been very supportive. I am surprised at just/ I would say over 95% of females maybe even higher than that. In fact only one person I, one person has been very non-committal and another person has been negative in having surgery. Just everyone else says that, "Oh you’re going to have it done? Don't waste time,” you know that sort of thing. Those are females. Men are a little bit more, don't really say too much, but you can almost, you know see in their faces. Oooh, you know, like you would do that?” (Unaffected mutation carrier)