“Getting on with it”:
New Zealand Women’s Experiences of Living with an Increased Risk of Breast and Ovarian Cancer

A thesis submitted for the Degree of Doctor of Philosophy (PhD) at the University of Otago

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Abstract

This thesis explores the experiences of a group of New Zealand women living with an increased risk of hereditary breast and ovarian cancer. The experience of living with increased cancer risk has been explored overseas; however this is the first study examining the experiences of New Zealand women. The study aimed to investigate the experience of living with an increased risk of breast and ovarian cancer, the ways in which women make decisions regarding genetic testing and risk management, and the impact of risk reducing salpingo-oophorectomy and mastectomy on body image and sexuality.

Qualitative, semi-structured interviews, and a narrative, thematic approach to the data analysis were used to explore the experiences and stories of thirty-two Pakeha New Zealand women who carry a BRCA mutation or who have a high risk based on their family history of cancer.

Decision making is an integral part of the experience of living with an increased risk of breast and ovarian cancer, as shown by earlier studies. This process begins with the decision to investigate the family history of cancer. Women go on to make a number of decisions regarding genetic testing, surveillance and surgical risk management. The influences on the decisions they make include the information they obtain, their perception of risk, their family experiences and their perceived responsibilities to their families. Decision making emerges as fluid, with decisions influenced by the woman’s specific circumstances and change over time.

“Getting on with it” has emerged as a dominant theme, as the way in which most of these Pakeha New Zealand women are approaching their risk. “Getting on with it” appears to be a deeply entrenched social, cultural and gendered expectation in New Zealand, perhaps influenced by our history as a settler society and the more recent influences of neo-liberal governance. Neo-liberal governance holds at its heart ideas regarding individual responsibility. These women, who are prepared to undergo significant, life-altering and potentially disfiguring surgery in order to be there to fulfil their family responsibilities, are living out dominant social and political expectations that we will each take responsibility for our own health and well-being.
Women choosing to have risk reducing salpingo-oophorectomy and mastectomy face the removal of body parts that are central to their identity and femininity. In particular, mothering is central to the identity of many of the participants. Many of the women with young children describe using their desire to “be there” for their children as they grow up, as the motivation to undergo risk reducing surgery. I argue that choosing to undergo the removal of healthy body parts in order to reduce risk and remain alive to fulfil role expectations provides a symbolic and gendered representation of women as carers and nurturers.

The implications of the findings for clinical practice in New Zealand are considered. Possible means of addressing issues identified by this group of women include greater use of multi-disciplinary clinics, development of more effective means of information provision and exploring the role of genetic counselling with whanau (family) groups.
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“Being deeply loved by someone gives you strength; loving someone deeply gives you courage.”

Lao Tzu
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Chapter One

Introduction

Genetic testing for hereditary breast and ovarian cancer

...she gave us the letter from the gene clinic... [30]. These words from Sarah¹, and other similar words, are used by a number of women to describe the moment when the diagnoses of cancer amongst their close relatives became something that involved them. The content of those letters from the genetic clinic, or that phone call from a family member, or the offer of a referral to Genetic Services made by a breast surgeon, oncologist or gynaecologist, altered the life of each of the women who participated in this project.

Sarah’s mother, Jane, died of breast cancer, which was diagnosed when she was nearing the age of fifty. Many years earlier, Sarah’s maternal aunt, Anne, had died of breast cancer aged twenty-one years. Anne had four small children who were adopted after the death of their mother. The rest of the family lost touch with these children. As a young woman, one of Anne’s daughters, Sarah’s first cousin, was diagnosed with breast cancer. While she was having treatment she got talking with another woman who was also having treatment for breast cancer. They realised that they were niece and aunt. After a second diagnosis of breast cancer, Sarah’s cousin was referred to Genetic Services for a risk assessment. As a result of this assessment genetic testing for hereditary breast and ovarian cancer was offered. She was found to carry a change in a gene associated with hereditary breast and ovarian cancer (called the BRCA1 and BRCA2² genes). By this time Jane had died. The genetic clinic gave Sarah’s cousin a letter to pass on to her family. She tracked down Sarah and her sister and gave them a copy of the letter. Sarah contacted the genetic service and she and her sister both decided to proceed with genetic testing for the BRCA mutation³.

¹ Where names are used, they are pseudonyms.
² These terms are defined in the glossary on page 265.
³ This term is defined in the glossary on page 266.
Since early 2000 genetic testing for hereditary ovarian and breast cancer has been available in New Zealand. Families with a high risk family history are offered a risk assessment by staff at Genetic Services and will be offered genetic testing if their family history meets the required criteria. If a mutation is identified in a family member who has had cancer, other family members, including those who have not had cancer, are able to have a blood test to clarify their own chance of developing certain cancers. This testing is offered through the Genetic Service and occurs in the context of a discussion with a genetic counsellor providing the individual who is considering testing with an opportunity to discuss the implications of both a positive and negative result. The decision to have testing may lead to many, often more complex, decisions regarding the way to manage an increased risk of cancer.

Sarah had a positive result. She decided that she was going to have her ovaries and her breasts removed, and went through with this surgery a few months after receiving her test result. She was forty years old. At the time of her interview Sarah was experiencing menopausal symptoms, with many hot flushes occurring each day. She had had months of regular visits by district nurses for dressings after the scars from the mastectomies and reconstructions became infected. She was inimitably cheerful and pleased by the decision that she had made, despite the difficulties.

1.1 The Study

This qualitative study involved semi-structured interviews with thirty-two Pakeha 4 New Zealand women who are living with an increased risk of developing ovarian and breast cancer. The study is the first to report on the experiences of New Zealand women, with the findings having the potential to contribute both to the understanding and future development of Genetic Services in New Zealand, and to the wider cancer screening and management services these women use. The findings also contribute to the growing body of international literature about the experience of living with cancer risk, serving to provide a New Zealand perspective on this experience. In addition, this study provided an opportunity for this group of women’s voices and stories to be heard beyond the boundaries of family and the medical services they access.

4 This term is commonly used to refer to New Zealanders of non-Maori descent, usually those with European ancestry.
The origins of the project developed out of my clinical practice as a genetic counsellor in the Central and Southern Regional Genetic Service\(^5\) in the first few years after publicly funded BRCA and mismatch repair gene\(^6\) testing became available as part of clinical practice in New Zealand. During those years I worked with a growing number of women who were at increased risk of developing ovarian and/or breast cancer because of a strong family history and/or because they carried a BRCA gene or Lynch syndrome\(^7\) mutation. I arranged predictive testing for one of the first young women in our service (aged in her twenties at the time) to have a BRCA test from which she received a positive result. I witnessed her distress at the result and the ensuing isolation resulting from not having another woman that we could put her in touch with to reduce her feelings of being the only woman living with this knowledge. It is often those experiences which linger in our memories that develop into research questions, and this experience was pivotal in fuelling my desire to better understand the experiences of this group of women. Much has changed in the ten years since clinical testing began. New Zealand now has a support group for BRCA mutation carriers (Gift of Knowledge) and Genetic Services have run information days for these families. There is a website run by an American based group, and this group also holds conferences for families with BRCA mutations (Facing Our Risk of Cancer Empowered).

During the early years of offering clinical testing, international studies were questioning the efficacy of screening for ovarian cancer using CA125\(^8\) measurements and transvaginal ultrasound, with recommendations that women consider risk reducing salpingo-oophorectomy\(^9\) becoming more wide spread. As a genetic counsellor, I frequently referred women to a local gynaecological oncologist to discuss management options. Women who were initially referred to the gynaecological oncology service were then referred on to genetic services for a more detailed assessment of their family history. The gynaecology service began to keep a record of the women who were at high risk, and the management decisions they made, as part of ensuring the women received appropriate follow up.

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\(^5\) This term is defined in the glossary on page 265.  
\(^6\) This term is defined in the glossary on page 266.  
\(^7\) This term is defined in the glossary on page 266.  
\(^8\) This term is defined in the glossary on page 265.  
\(^9\) This term is defined in the glossary on page 267.
In the course of my clinical work, I observed a wide range of experiences, behaviours and reactions to the experience of pursuing a genetic risk assessment for a family history of cancer. At the same time, an emerging literature from disciplines including sociology, psychology and genetic counselling began to explore the experience of being a member of a family with a strong history of cancer. Researchers in countries including Britain, North America, the Netherlands and Australia were instrumental in providing studies of families in their populations (see for example Babb et al, 2002; D’Agincourt-Canning, 2005; D’Agincourt-Canning, 2006; Hallowell, 1998; Hallowell et al, 2001; Hallowell & Lawton, 2002; Hallowell et al, 2004; Kenen et al, 2003; Lim et al, 2004; Meiser et al, 2000; Van Oostrom et al, 2003). In comparing the literature with my clinical experience, I began to consider how the experience for New Zealand women aligned with their overseas counterparts. The idea for this project arose out of a desire to understand the experiences of the New Zealand women with whom I worked, and to seek answers to questions regarding similarities and differences compared with other countries. I hoped to use the findings to continue to develop the service that New Zealand Genetic Services offer in ways that were directly relevant to women in the population that we serve.

While the conception of the project arose from a desire to explore New Zealand women’s experiences in a general sense, the limited number of studies that considered the impact of being at increased risk of cancers in organs that are central to a woman’s femininity, sexuality and body image was noted. The research proposal for this thesis involved an investigation of New Zealand women’s experiences of being at high risk of developing breast and ovarian cancer and the impact that this has on their body image and sexuality. The aims of the study included investigating their experiences of premenopausal risk reducing salpingo-oophorectomy and the effect this has on body image and sexuality and examining the ways in which women make decisions regarding risk management and the sources of information they use. The findings are set within the context of living with an increased cancer risk and the decision making that women undertake when considering how to manage their risk.
1.2 Background to the study

During 2005, the Todd Foundation Centenary Fund offered research funding to projects that were specifically related to rare inherited diseases. With support from my manager and the local gynaecological oncologist, I developed a research proposal and applied for funding. The project was to involve semi-structured interviews with women who had been identified as having a high risk of ovarian cancer by Genetic Services and who were now receiving care from the gynaecological oncology service. The project was successful in obtaining funding to contract an independent interviewer, the services of a typist to transcribe the interviews and travel funds meaning that women who lived outside the Wellington region could be invited to participate. The decision to pursue a PhD was made after the successful grant application, meaning that the questions for the thesis arose out of the proposal that had been developed for the funding application. In particular, the questions regarding the impact on body image and sexuality were used as a focus for the PhD project.

Ethical considerations for this study included the sensitive nature of genetic information as well as the aim of exploring the impact of cancer risk on body image and sexuality. Ethics approval was obtained through the Multi-Region Ethics Committee as women from a number of different District Health Boards were invited to participate (Appendix 1). The stated aims of the study were to explore the experience of genetic counselling, the ways in which women were making decisions regarding genetic testing and risk management and the impact on the women’s lives of these decisions. Prior to seeking ethics approval a letter of invitation and an accompanying information sheet were prepared. Minor modifications to the wording of the letter of invitation and the information sheet were made at the request of the Ethics Committee (Appendix 2). They also requested the invitation to participate be sent from the gynaecological oncologist as he held the database. While the aim of exploring body image and sexuality was implicit in the broader aims of the study, particularly the aim regarding the impact of decisions about genetic testing and risk management on individual women’s lives, this was not made explicit in either the invitation to participate or in the information sheet. The interviewer was asked to explain that this was a focus of the investigation during the process of obtaining consent and initiating each interview. In retrospect, and given the subsequent difficulties that the interviewer experienced when asking about body image and sexuality, including these topics in the initial approach to participants may have
allowed women to consider their willingness to discuss these personal topics and therefore whether they wished to participate or not.

The study utilised an independent interviewer with a background in sociological research and experience in interviewing families with inherited conditions, contracted to conduct the interviews. The decision to involve an independent interviewer was made because of the potential conflict of interest for me as a genetic counsellor, working in clinical practice, to conduct interviews with women with whom I had a prior clinical relationship. This decision and the ethical implications of having a clinical role at the same time as conducting research are considered in detail in chapter four.

While the interviewer had prior experience of interviewing people with and about genetic conditions, she did not have specific experience with interviewing about body image and sexuality. My experience in the genetic clinic when discussing risk reducing surgery, and my work supervising genetic counselling trainees, has taught me that women (both practitioners and clients) vary widely in their willingness to discuss these issues. Genetic counselling trainees, who are predominantly women, may also struggle with introducing topics related to risk reducing surgery and the potential impact on body image and sexuality. My experience has shown that it is the on-going exposure to these topics as part of a professional responsibility to ensure that women have access to adequate information for decision making that engenders increasing comfort with discussing body image and sexuality. This is also evident in the interviews, in that the later interviews contain more detailed exploration of topics related to body image and sexuality.

1.3 Introducing the participants

The women who were invited to participate in this study had all been or were currently patients of the Gynaecological Oncology Service at a tertiary, public hospital in Wellington, New Zealand. The women all had an increased risk of developing ovarian cancer. Due to the nature of the familial cancer syndromes involved, they also had an increased risk of other cancers, particularly breast cancer or bowel and endometrial cancer.
A close working relationship between the Gynaecological Oncology Service and the Genetic Service meant that almost all of the women had also attended an appointment with Genetic Services for assessment of their family history. A database of women attending appointments for a family history of ovarian cancer was maintained by the Gynaecological Oncology Service. There were seventy-one women on this database at the time that the project was initiated. A letter inviting them to participate in the project was sent to all of these women, along with an information sheet, an expression of interest form and a stamped return addressed envelope. The letters were signed by the gynaecological oncologist because the database was held by his service. Thirty-four women responded to the invitation to participate in an interview, two addresses were unknown and thirty-five women did not respond. Two women who responded to the invitation were unable to participate due to their geographical location. Interviews were arranged with thirty-two women.

New Zealand has a relatively small population which means that extra care must be taken to preserve the confidentiality of research participants (Tolich, 2001). The following description of the participants presents an overview of the group rather than a description of each participant, in order to maintain the confidentiality of each woman who was interviewed. A table is provided in appendix 3 to assist with this description.

The majority of the participants (twenty-two) lived in the greater Wellington region (including the Hutt Valley and Kapiti Coast). Women from Hawkes Bay, Taranaki, Manawatu, Nelson-Marlborough and Whanganui also participated, ensuring a cross-section of experience from women who lived close to hospital services and women who were travelling for up to several hours to attend appointments. Please refer to the map in appendix 4 for these locations.

The interviews occurred at participant’s homes or at another place of their choice. The majority of women were interviewed at home, with two women choosing to be interviewed in cafes.

The age range of the group was 25-66 years, with a cluster of women aged between their late thirties and early fifties.
As a group, these women were well-educated, with the majority having completed secondary school. Just over half the women had a tertiary qualification, including six women with post-graduate qualifications.

Most of the women were married (23) or partnered (4) at the time of the interviews, with five single women participating. Almost all of these women were in heterosexual relationships; however two women identified as lesbian.

The majority of women identified as European or Pakeha New Zealanders. Three women had immigrated to New Zealand, one from Canada and two from South Africa. At the time of recruitment for this study, there were no Maori or Pacific Island women on the Gynaecological Oncology Service database.

The referral patterns between Genetic Services and the Gynaecology Service meant that women could have been seen by either service first. Subsequent to their initial appointment with the gynaecologist, genetic testing altered the risk for some women.

Thirteen respondents had a family history of breast and ovarian cancer with no genetic cause identified. Genetic testing for BRCA mutations had been offered to the majority of these families and a mutation was unable to be identified. A few families were unable to have genetic testing as a DNA sample from an affected relative was not available. One woman had a clinical diagnosis of Lynch syndrome and an immunohistochemistry result suggesting that she carried a mismatch repair gene mutation but genetic testing had not identified a causative mutation.

Sixteen of the women interviewed for the study carried a cancer predisposition mutation; ten in BRCA1, four in BRCA2 and two in MSH2.

Two women had initially been assessed as being at high risk and had later been found not to carry a familial BRCA mutation. They had remained on the database and therefore received an invitation to participate. They both wished to be interviewed about their experiences.

The majority (twenty-four) of the women had not had a diagnosis of cancer themselves. Eight women had been diagnosed with cancer in the past, including four women with breast cancer, one with ovarian cancer, two with breast and ovarian/fallopian tube

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10 This term is defined in the glossary on page 265.
11 Further information about these genes is found in the glossary and in chapter three.
cancer and one with bowel cancer. The diagnosis of an occult fallopian tube cancer was made at the time of a prophylactic salpingo-oophorectomy in a woman who had had bilateral breast cancer and who chose to have risk reducing salpingo-oophorectomy after the identification of a BRCA mutation.\footnote{The terms prophylactic and risk reducing surgery are defined in the glossary on page 267.}

Women have several options for surveillance or risk reducing surgery, and these options are all represented by the respondents. Ten of the women described themselves as postmenopausal or were aged in their late fifties and sixties when interviewed. Six of these women had had a bilateral salpingo-oophorectomy when they were postmenopausal. Three women had not had their ovaries removed. They are from families where BRCA testing has been inconclusive or not possible and therefore the surgery may not have been recommended based on their family history. One of these women said she decided against it, another said she would have the surgery if she felt she was at risk, and the third woman had had a hysterectomy in the past that she had found very upsetting and, with the inconclusive BRCA result in her family, bilateral salpingo-oophorectomy was no longer indicated. One woman was diagnosed with ovarian cancer in her early fifties and had surgery as part of her treatment.

Four women described themselves as perimenopausal. Three of these women had had a bilateral salpingo-oophorectomy at the time of the interview. One woman stated that she was waiting until she reached menopause to have her ovaries removed.

Eighteen women were premenopausal at the time of the interview or had been premenopausal when they had surgery to remove their ovaries. Of this group, five women had had a bilateral salpingo-oophorectomy (aged 38, 40, 43, 43 and 45) and three women were due to have surgery in the weeks following the interview (aged 33, 40 and 47). One woman, aged 36, was planning to have a bilateral salpingo-oophorectomy when she was closer to 40. Several women were in the midst of having children or had not yet decided whether or not to have children. Two women seemed unsure about what they should do regarding the risk of ovarian cancer. One of these women was having annual checkups at the hospital and the possibility of bilateral salpingo-oophorectomy was not discussed during her interview. Another woman, aged 46, had had a hysterectomy for other reasons when she was 40, but had not wanted to become a menopausal woman at 40 so had retained her ovaries.
1.4 Ethnic disparity in New Zealand health care and its effect on this study

Ethnicity data collected by the Central and Southern Regional Genetic Service indicates that referral patterns reflect the ethnic demographic of the population that the service covers. The majority of clients identify as European or Pakeha New Zealanders, with smaller numbers of Maori, Pacific and Asian clients, as reflected in the population. In a study of the New Zealand experience of living with an increased cancer risk representation of Maori and Pacific Island people, who make up 14.6% and 6.9% of the New Zealand population respectively, would have been appropriate (Ministry of Social Development, 2009).

Disparity between ethnic groups in access to medical services and health care has been recognized by other researchers in New Zealand (Blakely et al, 2005). For example, there is some evidence to suggest that Maori tend to present for cancer treatment later than Pakeha, with increased mortality rates from breast cancer among Maori women compared with non-Maori (Sarfati et al, 2006). A recent study of the New Zealand Cervical Cancer Screening Programme found that Maori women tended to be less adequately served than non-Maori, particularly with regard to follow up of symptoms and abnormal smear results (Priest et al, 2006). These studies, along with the epidemiological work by Blakely and colleagues (2005), provide evidence of disparities by ethnic group and also by other factors including socio-economic status. Differences in screening behaviours among ethnic groups, as well as among women who are economically and educationally disadvantaged, have been documented in population screening programmes for cervical cancer (Priest et al, 2006) and breast cancer (Sarfati et al, 2006). Existing disparities in the health system in New Zealand may therefore account for some of the disparity in referral patterns for assessment of familial cancer risk and on-going surveillance. Port et al (2008) considered ways in which Genetic Services in New Zealand could enhance the service they provide to Maori, drawing attention to the importance of ideas regarding collective ownership of genes and DNA and collective decision making. They suggest that one way in which genetic services
may more appropriately serve Maori is by offering marae-based\textsuperscript{13} services to whanau\textsuperscript{14} and iwi\textsuperscript{15}.

Reviewing a number of international studies of families with hereditary breast and ovarian cancer, it is apparent the ethnic disparity in study participation is not isolated to New Zealand. For example Kenen et al (2003) report that, of the twenty-one women from the United Kingdom who participated in their study, one was black and twenty were white. Similarly, Hamilton et al (2009) report participation by one black American woman and forty-three white American women in their study. Babb et al (2002), Kenen et al (2006) and Werner-Lin (2007) all report entirely white participation. A number of other studies do not report ethnicity data (D’Agincourt-Canning 2005; D’Agincourt-Canning, 2006; Hallowell, 1998; Hallowell, 1999; Hallowell et al, 2001; Hallowell et al, 2004; Hallowell, 2006; Lim et al, 2004; Meiser et al, 2000).

The demographic of the women who participated in this study is similar to that seen by the Central and Southern Regional Genetic Service. The absence of Maori and Pacific peoples in this study may be indicative of disparities that are not just grounded in ethnicity. Instead they may reflect wider socio-economic disparities and perhaps also disparities in access to education. As discussed in chapter two, risk is a dominant construct of late modernity\textsuperscript{16}. It may be that risk is in fact not only a construct of late modernity, but that it is a concept that is specific to particular groups within our population. The demographic of the women who participated in this study, the majority of whom are Pakeha, well-educated, and in paid employment, indicates that all of these factors may play a role in influencing knowledge about the potential role of genetics in familial cancer, and having the time to pursue referral and then collection of family information.

\textsuperscript{13} Marae is the term used to refer to the meeting ground in front of a meeting house. The term may be more generally used to refer to the buildings and land that are in the common ownership of and iwi or tribe.

\textsuperscript{14} Whanau is the term used to refer to family, including extended family members. The term whanau ake may be used to refer to the nuclear family.

\textsuperscript{15} This term refers to a tribe or people.

\textsuperscript{16} The term late modernity is used by theorists including Ulrich Beck and Anthony Giddens to describe highly developed societies. These theorists consider this period as a continuation and development of modernity, hence the term late modernity. They do not see this era as a new state, as is indicated by the use of the term post-modernity by some theorists.
1.5 Theoretical and methodological framework

A range of disciplines have been drawn upon in the writing of this thesis. This is in recognition of the different fields where research has been performed that contributes to our understanding of living with an inherited cancer risk. Research has been undertaken in genetic counselling, social sciences such as anthropology, psychology and the biomedical sciences. Out of these varying disciplinary perspectives, particular concepts have emerged as pivotal to this project. These include concepts of risk and the effects of late modernity on our thinking regarding risk, the social construction of gender, concepts regarding mothering in the twenty-first century and the importance of the local on the experiences of the women who participated. The multi-disciplinary nature of the range of literature has been important both in conducting the literature review and in informing my understanding and interpretation of the data I collected.

Perhaps the most crucial concept to emerge as being central to understanding the experiences of these women is the concept of risk. Risk is constructed as the probability of an adverse event or harm occurring. Beck (1992) argued that late modern society is pre-occupied with the future, and with risks that might threaten that future. The concept of risk is constructed as something to be concerned about, something adverse or negative. Consider the way in which the meaning changes if the words “chance” or “possibility” are used in relation to the development of cancer. These words alter the meaning as they remove the implicit association of harm with the development of cancer. The concept of risk as something harmful or negative is beginning to be questioned, with research suggesting that there are in fact diverse responses to risk in the real world (Horlick-Jones & Prades, 2009). For some people, including many of the participants in this study, risk is constructed as a motivating and empowering concept, rather than as a concept implying harm.

A qualitative, exploratory study, drawing on research from a number of disciplines, provides an opportunity to further our understanding regarding the ways in which individuals manage risk and uncertainty in everyday life. Zinn (2005) suggests that putting the experience of health and illness into a biographical framework provides a way of conceptualising the experience. For Zinn (2005) the diagnosis of an illness represents a “defining moment” creating a rupture in an individual’s personal biography. Giddens (1991) uses the concept of “fateful moments” to describe a similar
idea, a moment in an individual’s life in which they stand at a crossroad that has significant implications for their future. Some of the women in this study have previously been diagnosed with cancer, so have experienced the diagnosis of a serious illness. Other women have received genetic test results confirming an increased predisposition to cancer, rather than the diagnosis of an actual illness. For these women, the confirmation of being at increased risk perhaps creates a similar defining or fateful moment, like the diagnosis of illness, and results in a renegotiation of self and of one’s future. Dagan and Goldblatt (2009) described this space between health and illness as a “twilight zone”, a place where one is neither ill, but nor is one perhaps completely well.

The importance of the local, New Zealand, perspective, and the influences of a voyaging and a colonising settler past, coupled with the more recent influences of neo-liberal thought, have given rise to a society in which expectations of “getting on with it” and taking personal responsibility for one’s own health and well-being are deeply entrenched. These influences are directly associated with a construction of risk as a motivating force to action. I would argue that the social construction of gender for women in New Zealand also plays an important role in influencing how women perceive risk and in the choices they make to manage future uncertainties. Women are brought up with implicit expectations that they will fulfil caring roles within their families, and also in their wider communities. Studies which explore the experiences of women who are mothering in the context of various risks (Barnes & Murphy, 2009; Elmberger et al, 2008; Kelly, 2009; Warin et al, 2008) highlight the tension between the empowering forces of maternal power and the burden of responsibility that women face as they make choices that they hope will allow them to remain alive to care for their children. For the women in the current study, these choices may include a trade-off between retaining or removing still-healthy body parts that are, along with their role as mother, central to their feminine identity.

The women who participated in this project talked about their bodies and about the meanings that particular body parts have for their identity as women, mothers, and partners. Their stories and experiences are considered within the greater context of the

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17 Neo-liberal is a term used to describe both market driven approaches to economic and social policy and to describe a prevailing ideological paradigm reflecting policies and practices that use the language of the markets, consumer choice and individual responsibility to shift responsibility from government to individuals and communities. Neo-liberal policies were introduced in New Zealand by the 1984 Labour government.
ways in which gender is played out in New Zealand. As with all societies, women in New Zealand are expected to conform to certain norms of femininity, both in appearance and in behaviour. Women who fall outside of societal norms may be questioned. This can be seen in the way that women who choose not to have children, who choose not to become mothers, are sometimes questioned about their decision in ways that women who do have children are not. A woman who considers not having a breast reconstruction or wearing a prosthesis after a mastectomy may be questioned because “breasts are the symbol of feminine sexuality” (Young, 1998, p.125). Breasts are viewed as central to the “look” of being a woman (Broom, 2001). It is often only when an individual chooses to step outside the socially expected norms of behaviour that we can begin to understand how deeply entrenched these expectations are in our society.

Feminist theory and practice underlie both the development and reporting of the project. In keeping with feminist praxis regarding providing a place for the voices of the participants to be heard, the words of the participants are included throughout the chapters reporting the findings. The women’s words are written in italics and the participant interview number is included in square brackets after each quote so the reader can follow the individual stories as well as appreciating the range of stories that were told. The majority of the women who participated in the project were middle class, Pakeha New Zealanders, many of whom have tertiary education. In writing this thesis, I have made a purposeful attempt to present the findings in a way that is accessible to a group of people beyond the academic audience and that includes the women who participated.

1.6 Thoughts on becoming a practitioner-researcher

When I began this study, it was with the hope that the findings would contribute to the growing literature exploring the experience of being at increased risk of cancer. In particular, I hoped to explore the ways that New Zealand women approach their risk. With rapid advances in molecular genetics, it will become increasingly possible for individuals to seek genetic information regarding the possibility of increased risk for common, adult onset, multi-factorial conditions including cancer and cardiovascular disease. During the period of late modernity the term “risk society” was coined to
describe the experience of living in a modern society where previously unknown risks are becoming increasingly prevalent (Beck, 1992). These risks include the effects of pollution and the flow-on effects on many aspects of modern life. Increases in certain diseases and in health risks associated with modern Western living are an important aspect of life in a “risk society”, an aspect which many people seek to control or limit in a variety of ways. The increasing availability of ways to identify who carries an increased risk of developing one or more of a number of common diseases such as cancer and cardiovascular disease provides at least some individuals and sectors of society with information and the potential to act to minimise or reduce the risk. As access to this type of “predictive” information becomes more widely accessible, it is crucial that we further develop our understanding of what it is like to live with an increased health risk and of the types of information and support that those who seek clarification of their individual risk desire.

I approached the project from a position of relative knowledge in that I had been working as a genetic counsellor in New Zealand for several years. As will be discussed in chapter four, I came to regard myself as an “outsider alongside” the participants as a way of acknowledging the additional information and knowledge that my clinical work affords me, while at the same time acknowledging that I do not know what it is like to live with this particular risk. As all projects of this nature should, the process of data collection, analysis and literature review has taken me on a journey that has caused me to question the very nature of the work that I continue to do on a daily basis. Through extensive reading I have come to understand the positioning of genetic counselling inside a wider discourse of public health and beyond that within the setting of neo-liberal discourses regarding personal responsibility. I have struggled with finding ways to represent and write about the experience of being at risk for ovarian cancer in ways that fairly and honestly represent the stories that each of the participants told. In particular, I have struggled with the presentation and language to describe the experiences of the small group of women who themselves struggle with their increased cancer risk.

In doing this project I have uncovered my own biases and those of the health system within which I trained and continue to work. I have come face to face with my own, previously unconscious, expectation that knowledge of increased risk provides power and choice in managing and reducing that risk. This expectation is implicit in the
situating of cancer genetic counselling “at the intersection of discourses of choice and autonomy and discourses of solidarity and responsibility” (Koch & Svendsen, 2005, p. 831). The expectation is made explicit by the findings of a study of genetic counselling appointments for hereditary cancer that noted that the option of “doing nothing” was rarely, if ever, presented to attendees (Hallowell, 1999). Quite simply, attendance at the genetic clinic and the provision of a familial risk assessment is positioned in the health system as the first step in a process of reducing risk and therefore of reducing the potential for a future diagnosis of cancer, with its attendant need for costly treatment. The expectation is that individuals will take action to reduce their personal risk of developing cancer.

Finding the language that fairly and neutrally represents the experiences of women who have appointment letters for mammograms that they have not attended, or who have not followed up on additional information has been particularly difficult. Words such as “doing nothing” have significant negative connotations and may in fact belie the truth for these women. While medical models may view non-attendance at surveillance appointments as “doing nothing”, these women may be pursuing other activities that help them live with their increased cancer risk, which were not explored or considered in this study. Finding ones way into the medical system and then negotiating appointments for tests and with doctors and allied health practitioners can be daunting even for those of us who are familiar with the way that the system works. The intersection of my training in a medical system that implicitly regards action as desirable, and my own personality which tends towards action, means that I have struggled to fairly represent the experiences of a small group of these women.

1.7 Outline of the thesis

Chapter two discusses the literature that has influenced my thinking and understanding of the data collected for this project. The concept of risk is pivotal to the project, with risk considered as a construction of late modernity. Risk has been interpreted as being synonymous with harm; however recent research is beginning to challenge this view, suggesting that for some people, risk is seen as a motivating force promoting actions that have a strongly future-oriented aspect (Austen, 2009; Horlick-Jones & Prades, 2009). Risk perception, involving subjective judgments about a possible event, is
considered with a view to gaining insight into the way in which individuals incorporate their lived experiences of an event into their understanding of risk.

This project examines Pakeha New Zealand women’s experiences of their bodies in the context of an increased risk of developing cancers that particularly affect women. The social construction of gender and the influence of societal perceptions and beliefs about femininity and women’s bodies are considered. Essential to the project is an understanding of what it means to be female in New Zealand in the first ten years of the new millennium. Finally, this chapter considers a range of literature about living with an increased risk of cancer, drawing on both qualitative and quantitative methodologies to understand this experience.

Risk assessment and genetic testing for familial cancer is situated within the public health system in New Zealand. Chapter three begins with an outline of the social context of health care in New Zealand and of genetic testing for hereditary cancer. The chapter provides a detailed account of the risk assessment process and the genes that these women carry. Women who carry a gene that results in an inherited predisposition to ovarian cancer have limited risk management options as surveillance for ovarian cancer has not proven effective in identifying early stage, treatable ovarian cancers. Risk reducing salpingo-oophorectomy is discussed, as it is the currently recommended management option for women with BRCA mutations. Many of these women have an increased risk of developing breast cancer and the management options are reviewed. A few of the women who participated in the study have Lynch syndrome and therefore have an increased risk of developing colorectal, endometrial and ovarian cancer. The management guidelines for women with Lynch syndrome are discussed.

Chapter four provides a discussion regarding the methodological and theoretical underpinnings of the project. This project is underpinned by feminist research theory, with the focus on allowing the voices of the women who participated to be heard and accepting that the findings of the project are of the collective and shared experiences of the participants, resulting in an extension of existing knowledge. The importance of using the findings to influence future service planning and delivery is recognized. The position of the practitioner-researcher is considered and the notion of researcher reflexivity is explored as a means of highlighting the ways in which my position as an
outsider alongside the participants impacted on the research from the point of design through data collection, analysis and writing.

Earlier research which influenced the development of the current project is considered. No studies of this kind had been done in New Zealand, so this project drew on overseas literature and was designed to report the experiences of New Zealand women, with our unique cultural and social life views. The study design utilized semi-structured interviews and a narrative thematic analysis. The challenges that arose regarding helping participants to talk about the impact on sexuality and body image are discussed. Finally, the role of writing as part of the analysis is considered.

Chapter five introduces the voices of the participants and examines the decisions that they have made as a result of being a member of a family with a hereditary cancer syndrome. In this, the first of the discussion chapters, I draw on a number of fields to build a new account of the stories that these New Zealand women told about living at increased risk of hereditary ovarian cancer. Review of the literature that influenced the development of this study suggested that decision making was likely to be a salient theme for the participants. The chapter starts with a description of several stories representative of the women’s experiences. The stories outline the different circumstances within which the information about the increased risk is experienced and decisions regarding risk management are made. The stories make explicit the ways in which the information regarding risk and the perception of that risk are situated within the experiences of the woman and her family. Information emerges as a critical factor for these women, with gaps in the provision and receipt of information identified and discussed. Decisions include risk management, followed by a series of often overlapping decisions about the type and extent of surgery, the use of hormone replacement therapy, who to discuss their risk status and management plans with, and, for a few women, decisions regarding the use of prenatal technology. The material in this chapter provides the foundation for the three chapters that follow.

Chapter six provides a detailed examination of the ways in which this group of New Zealand women approached the increased risk of cancer and the ways in which their approach was influenced by societal, political and gendered discourses. These women identify their many roles and responsibilities, situating their family history and their personal cancer risk as just one aspect of their lives. In keeping with this, the
predominant approach to the risk is to “get on with it”, an approach that appears to be a gendered and societal expectation that reflects the New Zealand way of life. Genetic counselling, both in New Zealand and internationally, is increasingly situated in a health setting that promotes health and well being and that is overlaid with societal, cultural, political and gendered expectations of individual responsibility. The finding that women “get on with it” has seldom been reported in the familial cancer literature, and I suggest that this is because it is a pervasive societal expectation that is so deeply entrenched in Western society as to go unnoticed.

A few women struggle to “get on with it”. These women report uncertainty and feelings of powerlessness in their interactions with health professionals. There are important implications for clinical practice and service delivery in the finding that a small group of women may be lost to follow up as they struggle to make their way through the medical system. Other factors that appear to influence the ways in which women approach their risk include worry, a very pervasive fear of cancer, and the determination to fight this disease from some women. A few women described a feeling of safety associated with carrying a BRCA mutation, suggesting that it made them more interesting to medical specialists. Ways of approaching risk tend to run in families, with women often describing the ways their mothers, aunts and sisters coped with the risk of cancer.

Chapter seven examines the influence of being a mother on the decisions and experiences of the participants. The majority of the women who participated were mothers and mothering emerges as a powerful motivating force towards action to reduce risk. These women voice a deeply felt responsibility to be there to care for their children. Mothering and femininity are entwined and the identity and role of mother reinforces a woman’s gender identity. Both mothering and femininity are impacted by the increased risk of ovarian and breast cancer for this group of women. The influence of the responsibilities that come with being a mother on surgical decision making are discussed. It has been suggested that the notion of “getting on with it” has a temporal orientation towards the future (Roberts & Clarke, 2009) and it appears that the influence of the desire to see one’s children grow up is a strongly motivating force for many of these women. This concern with survival to fulfil role responsibilities, particularly those associated with mothering, has been reported among women living with various risks. As with femininity, motherhood and sexuality are inextricably linked. The split between motherhood and sexuality becomes tangible for women who choose to manage their risk.
surgically. This chapter closes by examining the experience of telling children about the cancer risk in the family.

Chapter eight explores the women’s experiences of risk reducing salpingo-oophorectomy and bilateral mastectomy, acknowledging the vulnerability and changes to identity that accompanies the removal of *womanly parts*. The women in this study appear to be influenced by both feminist and biomedical models of menopause, with women raising concerns about the physical symptoms of menopause and the difficulties with maintaining a recognisably feminine body, and at the same time acknowledging that the surgery simply brings forward the timing of a natural life transition. The language that the women use to describe their ovaries and breasts suggests an emotional distancing from body parts that were once liked, but which have now become a site of unacceptable risk. In contrast, they report doctors using a language of deficit, reinforcing biomedical models which have historically lacked respect for women’s bodies and view body parts such as breasts and ovaries as dispensable objects. While previous work suggested that breasts are an important part of the way a woman looks and ovaries are important to the way that she feels (Hallowell, 1998), the current work suggests that functioning ovaries and the presence of female hormones are in fact important in maintaining a body that is recognizably feminine. The comments regarding the feel of reconstructed breasts indicate that, while having a breast shape may make a woman look like a woman, in fact the feeling of their breasts is significant to these women.

Chapter nine considers the ways that the findings of this research may be used in clinical practice, both in New Zealand and overseas. The findings suggest that the majority of New Zealand women will “get on with” their lives, incorporating their increased chance of developing cancer by doing what they can to manage the risk. Many of the women interviewed for this study have a clear future orientation and a desire to be there, to be alive, and to raise their children. They identify gaps in service provision, both in the information that was available to them and in ongoing support. In this chapter I suggest that the use of multi-disciplinary clinics may be one way of providing more adequate and timely information, ongoing support and a “safety net” for women who struggle to “get on with it”. The ways in which the findings from this study can inform clinical practice are considered. Chapter nine considers the limitations of this study and offers suggestions for further research to address these concerns. A
project such as this is inevitably a journey that includes reflection. I offer my reflections on this journey and on the ways that undertaking research while simultaneously working with women who are facing the same issues as the women in this study has influenced my practice.
Chapter Two

The impact of new knowledge on the everyday lives of New Zealand women: A review of the literature

We live in a world in which the rapid expansion of knowledge and technology creates new opportunities and ways of living. Individuals, communities and societies must find ways to incorporate the expansion of knowledge into their everyday lives. Theorists Anthony Giddens and Ulrich Beck have both considered the ways in which new technologies are creating risks and uncertainties in this period of late modernity (Beck, 1992; Giddens, 1991; Giddens, 1994). This chapter considers the nature of risk and the way in which risk is understood in the twenty-first century, along with a consideration of the factors that influence an individual’s perception of any given risk. This study is about New Zealand women, women’s bodies, and about living with an inherited, genetic risk of developing cancer in organs that are specifically female. The writing that has influenced my thinking and understanding of women’s bodies and of the ways in which gender operates in New Zealand society today is discussed. Finally, the existing literature, drawn from a number of disciplines, which examines the experience of having an inherited cancer predisposition and the available risk management options, is considered.

2.1 Theorising Risk

In order to gain an understanding of the experience of living at increased risk of developing cancer, it is necessary to consider the meaning of the word risk and the way that this term has come to be used in the present day. The term risk is sometimes used as a synonym for “harm” but is also a concept that relates to the management of future uncertainties (Giddens, 1991; Zinn, 2005). The concept of risk is not new, but during late modernity people have become more concerned with the future, resulting in a preoccupation with risks that might threaten that future. At a global level risks that have arisen as a direct result of modernisation and of scientific and technological advances include pollution, increasing crime rates, political instability and the appearance of new
Ulrich Beck (1992) used the term “risk society” to describe a society which is organised in response to risk, suggesting that this was true of society in late modernity. Individuals have become increasingly responsible for managing a range of risks, some of which may potentially be life threatening (Alaszewski & Coxon, 2008). With the rise of neo-liberal thinking and governance there has been a concomitant rise in effecting governance through citizens who are responsible for managing themselves and their relationship to risk (Petersen, 1998; Petersen, 1999).

The risks Beck described crossed national boundaries and boundaries of time to affect future generations and communities (Lash & Wynne, 1992). These hazards take the form of ecological and high technology risks that endanger all forms of life on the planet, with a focus on hazards that cannot be seen (Beck 1992).

Genetic or inherited risks, such as those posed by the presence of a BRCA gene mutation have some similarities with the risks Beck described, in that they are unseen and cross boundaries of time, affecting past, present and future generations. While families will have long been aware of the number of cancer diagnoses among their relatives, it is only through relatively recent scientific and technological advances that individuals have been able to access information that allows them to clarify their individual risk. Beck (1992) aptly described the risk potential conferred by a genetic predisposition to cancer and the potential to reduce risk when he discussed the “Not-Yet-Event” as a stimulus to action (p. 33). He said: “We become active today in order to prevent, alleviate or take precautions against the problems and crises of tomorrow and the day after tomorrow – or not to do so” (Beck, 1992, p.34). For Beck (1992), risk is a negative concept that is aligned with uncertainty and worry for individuals. He suggested that in situations where there appeared to be no escape from risk, which it could be argued is the case with an inherited cancer predisposition mutation, “people ultimately no longer wanted to think about it” (Beck, 1992, p. 37). Beck (1992) appears to contradict himself when he notes that safety is a motivating force in a risk society, as this suggests that individuals can choose to use the potential for risk to motivate actions to keep themselves safe from that risk. This suggests a positive aspect to risk. Indeed, Alaszewski and Coxon (2008) note that individuals are “actively engaged in managing their everyday lives and that risk is one resource that they choose to use in this process” (p. 418–419).
Anthony Giddens (1994), conceptualising risks associated with modernity during the same period as Beck, also focuses his discussion on the risks and uncertainties associated with the effects of globalisation and the ecological crisis that is facing the earth. He suggests that as a result of the human socialisation of nature we are faced with a range of possible scenarios, making life akin to a dangerous adventure in which we are all participating. However, Giddens (1994) believes that human beings have the potential to find opportunity when faced with risk. Like Beck, Giddens (1994) draws attention to the ways in which the growth of human knowledge has created some of the uncertainties and risks that individuals and communities face today. This can be clearly seen in the field of cancer genetics, with advances in genetic testing creating both new knowledge and new uncertainties for individuals and families.

While the concept of a risk society has had a significant influence on theorising in the past twenty years, some scholars are beginning to question the dominance and use of this concept (Austen, 2009; Horlick-Jones & Prades, 2009). Austen (2009) conducted research with adolescents to test the applicability and relevance of the risk society discourse to this group. She found that the young people in her group did not appraise risk negatively; rather, they regarded risk as a neutral concept that could have positive as well as negative outcomes. Austen (2009) found that the adolescents in her sample did not promote feelings of uncertainty regarding risk, which conflicts with Beck’s (1992) assumption that risk is aligned with worry and uncertainty. Horlick-Jones and Prades (2009) also suggest that the model of reflexive modernisation posed by Beck and Giddens is limited in its “capacity to capture the full diversity of risk-related practices that may be observed in real-world settings” (p. 415). Risk may therefore be conceptualised both negatively and positively, depending upon the context within which the perceived risk is occurring.

The experience of living with risks of different types has been explored in a number of studies in recent years, perhaps due to the recognition that individuals are confronted with a multiplicity of different risks during their lifetimes (see for example Barnes & Murphy, 2009; Crouch & McKenzie, 2000; Dagan & Goldblatt, 2009; Elmberger et al, 2008; Kelly, 2009; Kenen et al, 2003; Morris, 1999; Roberts & Clarke, 2009; Rowley, 2007; Werner-Lin, 2007). In the editorial to a recent edition of Health, Risk and Society, Clarke (2009) explores several key risk concerns that she believes are helpful in understanding risk in the context of living with long term conditions. Two of these
concerns are particularly relevant to the situation for people who have an inherited cancer predisposition. Firstly, Clarke (2009) notes the tension between seeing a long term condition as disabling and therefore catastrophic, and seeing the same condition as life enhancing. Individuals may report a narrative of shock and distress at the time of diagnosis, but later a counter-narrative of hope and recovery appears.

Clarke (2009) also notes the tension between autonomy and safety, with risk being used to promote both safety and autonomy. This tension is apparent in the discourse of the genetic clinic. Koch and Svendsen (2005) argue that approaching a genetic clinic for assessment of the family history of cancer is the initial step for an individual in managing their cancer risk. This implies that, for example, a woman who carries a BRCA mutation will take steps to reduce her risk, and thereby increase her safety, by having risk reducing surgery. At the same time, the practice of genetic counselling has been heavily influenced by discourses of individual autonomy and informed choice, creating tension between the implication that an individual will proactively use the risk information they are given, and the desire to support an individual to make an autonomous choice regarding the use of that same information. For some individuals an autonomous choice will mean choosing not to have risk reducing surgery, although an earlier study found that this was not usually presented as an option to women undergoing genetic assessment for a family history of breast and ovarian cancer (Hallowell, 1999). Historically, the practice of genetic counselling was based on the concept of rational decision making, with the assumption that individuals would make “rational” decisions when provided with risk information (Petersen, 1998). This assumption denies the complexity of social action, with the risk estimate only one influence in an individual’s decision making (Petersen, 1998). The construction of medical interventions to manage the risk are understood as the responsible and appropriate way in which to behave for health practitioners involved in genetic counselling (Hallowell, 1999). This construction of responsible behaviour associated with active medical management of risk indicates that risk is used to promote safety in the genetic clinic. However, it fails to consider alternatives to medical management of cancer risk. In ignoring alternatives to medical approaches to managing the risk, it could be said that the genetic clinic is failing to promote client autonomy because the clients are not making decisions based on knowledge of the risks and benefits of a range of possible options for managing risk.
People arrive at the point of diagnosis of a serious illness, or the finding that they carry a cancer-predisposing mutation, with biographical resources which influence how they manage and respond to the diagnosis (Zinn, 2005). These resources include both what an individual has previously experienced in life as well as the experiences they have not had, their “disappointed desires” (Zinn, 2005, p. 5.). The influence of previous experiences and hoped for future experiences can be seen in studies with women mothering in the context of a number of different risks. These studies include Elmberger and colleagues’ (2008) study of mothers with cancer, Roberts and Clarke (2009) study of women with gynaecological cancer and the study by Kelly (2009) about intimate partner violence. These studies all demonstrate the powerful influence of the experience of being a mother in influencing decisions about management of present risk. In addition it could be argued that these studies highlight the importance of future desires, for example being there to see one’s children grown, in influencing current decisions about health and safety.

Once an individual becomes aware of a risk or uncertainty, they may make decisions regarding how to manage the risk. The current literature regarding management of risk and uncertainty suggests that individuals now live in a society in which many complex decisions are required and in which there may be little time to make these decisions. Individuals therefore call upon a number of strategies to make decisions which may include rational strategies including the weighing of benefits and harms, calculation of the actual risks, and means of insurance; non-rational strategies including belief, hope, faith and avoidance; and “in between” strategies (Zinn, 2008). “In between” strategies include trust, intuition and emotions, which overlap with each other and which may include facets of both rational and non-rational decision making (Zinn, 2008). Trust involves a combination of experienced-based knowledge, intuition and emotions and is used to assist in reducing the complexity of some forms of decision making (Zinn, 2008). For example, a woman might choose to put her trust in a known individual who has expert knowledge, skills or experience in caring for individuals who carry cancer predisposing mutations. Intuition refers to experience-based, pre-rational assessment of a situation and may involve concepts such as the use of heuristics (inferential shortcuts) in decision making (Zinn, 2008). Kenen et al (2003) showed that women from families with hereditary breast and ovarian cancer use heuristics to make sense of the complex genetic and risk information that they are given. Finally, emotions are involved in both
trust and intuition and are an important aspect of decision making regarding uncertainty (Zinn, 2008). The brain tends to respond quickly to emotions, providing a “gut feeling” response to managing uncertainty. This may be followed by a slower, more rational, consideration of the alternatives.

2.2 Risk perception

One of the ways in which we can begin to understand the decision making process women at high risk go through is to consider the matter of risk perception and the factors involved in a woman’s interpretation of her individual risk. Risk is conceptualised as a “combination of probability and something adverse, unpleasant, or dangerous” (Palmer & Sainfort, 1993, p. 275). One of the fundamental strands of genetic counselling is risk assessment and the communication of risk to clients (Weil, 2000). In the cancer genetic counselling setting, the provision of risk information and options for risk management is seen by genetic clinicians as integral to the counselling, so understanding how people construct and understand risk is crucial to the provision of effective genetic counselling (Sivell et al, 2008).

Risk can be presented in a number of different ways. Risks can be presented as ratios (for example, 1 in 4) or as percentages (25%). Verbal descriptors can also be used to describe and attempt to clarify an individual’s perception of a figure, for example high, medium or low risk (Weil, 2000). Women coming for cancer genetic counselling may be told that they are at high, moderate or population risk of developing certain cancers. Those women who carry a cancer predisposition mutation are likely to be given statistical risks of developing certain types of cancer, for example, women with a BRCA mutation have a 20-40% lifetime risk of developing ovarian cancer. Individuals vary in their interpretation of the same risk figures. There are several reasons for this, including the fact that it is impossible to separate the probabilistic elements of risk from the meaning and implications of the outcomes of the risk to different individuals (Edwards, Elwyn & Mulley, 2002).

Individuals apply descriptive terms differently to the same numeric risk (Palmer & Sainfort, 1993) and genetic counsellors use different verbal descriptors for the same numeric risk, depending on the situation to which the term is being applied (Burke &
Kolker (1994). Bjorvatn and colleagues (2007) compared people’s interpretation of risk when presented as a percentage figure and as words (for example “unlikely”, “no doubt”) and found that there was a large range in percentage for each word category, suggesting that it is difficult to know or interpret how people understand risk. In other words, verbal descriptors can be an unreliable method for communicating risk (Weil, 2000). Sivell and colleagues (2008) conducted a systematic review of the literature regarding the way in which risk is perceived, constructed and interpreted by people coming to genetic counselling. The evidence from the studies reviewed suggested that most people find it difficult to accurately quantify their risk.

While risk is a concept that denotes the probability of a specific event, for example the probability of developing ovarian cancer, risk perception involves the subjective judgement that an individual makes regarding the characteristics and severity of that risk. In other words, risk perception involves the way in which an individual interprets and makes meaning of the risk figures they are given. Palmer & Sainfort (1993) point out that adversity is not inherent in a genetic disorder - someone has to ascribe this meaning to the disorder. Once this meaning has been ascribed to the event, the possibility of the event occurring is perceived as “risky” as opposed to “chancy” (Palmer & Sainfort, 1993).

Numeric risk figures constitute only part of an individual’s perception of risk. Other factors are involved in how an individual makes meaning of that numeric risk figure, meaning that individuals have different interpretations of any given condition and its burden. Sivell et al’s (2008) review of a number of studies exploring how individuals understand risk suggest that it is experiential and affected by an individual’s lived experience. Lippman (1999) studied the ways in which women make decisions regarding amniocentesis and found that women negotiate with the biomedical information they are given and transform it into what she describes as an “embodied” knowledge. In other words, women combine their own experiences, instincts and beliefs with the factual, probabilistic information which they are given, and from this a decision regarding prenatal testing is made.

Women attending genetic counselling for familial breast and ovarian cancer are likely to pursue a similar process of combining factual, probabilistic information with their own experiences. A number of studies have reported that a woman’s personal and family
history of cancer, and her involvement in caring for relatives with cancer contribute to her perception of the risk of developing cancer (D’Agincourt-Canning 2005; D’Agincourt-Canning, 2006; Hamilton et al, 2009; Kenen et al, 2003; Lim et al, 2004; Meiser 2005; Metcalfe et al 2008). A recent study found that the uptake of risk reducing mastectomy was significantly higher in women who have a sister with breast cancer and women with a mother or sister with ovarian cancer were significantly more likely to have a risk reducing salpingo-oophorectomy than women without a first degree relative with ovarian cancer (Metcalfe et al, 2008). Other factors such as how a woman feels about bodily integrity, that is, how she feels about surgery to remove healthy tissue, and how important her breasts and ovaries are to her self-image and her sense of being a woman also contribute to risk perception and what she is prepared to do to manage that risk (Hallowell, 1998).

Genetic counsellors provide women with objective or quantifiable risk information and they also provide an opportunity for the women to start to explore and make meaning of their situation (Sivell et al, 2008). A number of studies have explored the ways in which people perceive their risk of cancer (Bjorvatn et al, 2007; Keller et al, 2008; Meiser & Halliday, 2002), particularly comparing their perception of their risk of developing cancer prior to and after genetic counselling. These studies showed that genetic counselling improves the accuracy of an individual’s understanding of their risk. However, a quantitative understanding of risk is only part of the puzzle. Researchers are beginning to explore and understand the ways that individuals make meaning from the figures they are given, but further research and models for genetic counselling practice are needed if genetic counsellors are to provide people with the best care possible.

2.3 Theorising gender

“[o]ne is not born, but rather becomes, a woman”

These words, by Simone de Beauvoir (1988/1949, p. 295) provide a central principle to our understanding of gender. Gender is a term that has been used since the 1970s to describe the ways in which people and practices are divided along the lines of sexed identities (Beasley, 2005). In order to appreciate our current understanding of gender, it is necessary to consider the contributions of both structuralism and post-structuralism.
Gender is a way of structuring social practices (Connell, 2000), with gendered positions occurring through these social practices (Lorber & Moore, 2007). Individuals are divided into two categories – women and men – and these categories are used to organise society. Institutions such as work, family, education and religion are all organised in relationship with the categories of male and female. Bodies are important in linking individuals with social structures (Holmes, 2007), with Connell (2000) suggesting that everyday life is in fact organised around the reproductive arena.

Theorists such as Connell (2000) suggest that gender is constructed by social structures including power, production, emotions and the symbolic. In this model gender consists of several structures and different patterns may be seen within these structures, for example, the patterns may differ between economic relationships and emotional relationships. The main axis of power has long been the overall subordination of women by men, which feminists have named patriarchy. Gendered divisions of labour are familiar to us all, and these divisions have economic consequences, with men accruing unequal shares of the results of labour and production. Connell (2000) goes on to discuss the ways in which communication, which is a vital element of social processes, is an important site of gender practice. For example the subordination of women is reflected in linguistic patterns whereby titles for women define them by their relationship to men.

Post-structuralist thought holds that gender is what we do, not what we are (DeFrancisco & Palczewski 2007). The work of Judith Butler is perhaps most influential in developing our understanding of gender as performatve, (something that is produced through the repetition of gender norms) (Holmes, 2007). These ideas extend our understanding of the social construction of gender by suggesting that gender is in some senses imposed on us (Holmes, 2007), with gender differences maintained by both individuals and institutions (DeFrancisco & Palczewski 2007). As illustrated in the quote by Simone de Beauvoir, the influences and practices of societies and cultures create women and men and inform our ideas about femininity and masculinity.

The historical and social structures that shape gender change with time (Connell, 2000) as do the meanings of masculinity and femininity (DeFrancisco & Palczewski 2007). Each individual makes choices about how to “do” gender, with these choices being made in relation to the patterns and norms of femininity or masculinity that are
dominant at the time and within the society that the individual is a part of (Holmes, 2007). This would suggest that ideas and constructs that are current at any given time are influential in our understanding of gender.

In the late modern era concepts of risk and the management of risk have dominated theorising and are therefore likely to influence the ways that gender is understood. This can be seen in research that explores the way people respond to risky situations, with women often reported as being positioned to take responsibility for risks that they and their families may be exposed to. For example women experiencing intimate partner violence are positioned as having responsibility for the safety and well-being of their children (Kelly, 2009) and accounts of rape suggest that (male) offenders may minimize their responsibility, and instead pass responsibility for their actions to the woman (Jordan, 2005).

Chris Weedon (1987) notes that self sacrifice is one of a number of qualities thought to be feminine in nature and origin, a suggestion that is echoed by Medina and Magnuson (2009). Holmes (2007), drawing on the work of psycho-analyst Nancy Chodrow, suggests that young girls develop their understanding of what it means to be feminine through their mothers role as a mother. They learn from their mothers that being feminine is about being nurturing and caring and putting the needs of others before one’s own needs. Dominant expectations regarding self-sacrifice and putting the needs of others before themselves may go on to influence a woman’s understanding of risk and the choices she makes to manage specific risks.

Research must be considered in relation to dominant beliefs and understandings about gender, particularly when the research is directly related to women’s bodies. As will be seen below, cultural expectations require women to adorn themselves in ways that will make them sexually attractive to men (DeFrancisco & Palczewski 2007). Women are bombarded with images and messages informing them of what they should look like and how they should behave, and are then judged by how well they fit with the prevailing cultural norms (DeFrancisco & Palczewski 2007; Reel et al, 2008).
2.4 Theorising gender in New Zealand

Discourses of nationhood are brought to us in many ways including through powerful images of New Zealand and “New Zealandness” depicted in many forms of media. Perhaps one of the most powerful recent examples of media depicting what it means to be “Kiwi” is found in the movie Untouchable Girls, about the lives and careers of the Topp Twins. In reviewing the film, Lynda Johnston (2009, cited in Brady, 2010) drew attention to the depiction in the film of a number of major social and political movements of the past 30 years, including the 1981 Springbok tour, the nuclear-free New Zealand movement and the homosexual law reform debates, that have helped shape ideas about “what it feels like to be Kiwi” (pp 70, cited in Brady, 2010, p.12).

For journalist Steve Braunias, the New Zealand identity, or “what it feels like to be Kiwi,” is “bound up with a profound sense of belonging to where we live” (quoted in Macdonald, 2010, p. 15). Braunias has recently embarked on a writing project arguing against Gordon McLauchlan’s 1976 book The Passionless People. In contrast to McLauchlan’s portrait of New Zealanders as passionless, in an article by Nikki Macdonald (2010), Braunias described New Zealanders as a “self-effacing people” (p.14) who are “extremely expressive” (p.15) and who have an omnipresent sense of humour. He believes that, as New Zealanders, we bring a distinct feeling of New Zealandness with us when we enter a room.

The sense of belonging to where we live is perhaps partly associated with the land New Zealanders call home. New Zealand is a geographically isolated nation, a group of islands situated in the midst of an ocean several thousand kilometres from our nearest neighbours. The islands were initially settled by Maori, who voyaged thousands of kilometres in waka¹⁸ to settle these islands. The initial decades of European settlement in New Zealand were dominated by migration by men who worked as whalers, sealers and sailors. However, after the signing of the Treaty of Waitangi¹⁹ in 1840, a more organized and formal period of migration, predominantly from the United Kingdom and Ireland, began. Men still outnumbered women during this period, although young,

¹⁸ A waka is a canoe.
¹⁹ The Treaty of Waitangi is the founding document for New Zealand. It represents an agreement with regard to the broad principles of establishing New Zealand as a British colony, made between the British Crown and over 500 Maori chiefs. It was first signed in Waitangi on 6 February 1840.
single women were encouraged to migrate to work as domestic servants and to become the wives of men who had already settled here (Levesque, 1986). Whole families also immigrated during this period. It was understood that the women immigrating during these early years needed a degree of toughness and willingness to work hard (Adam, 1874). These migrants made long, difficult voyages by sea to settle here, leaving behind their extended families and friends, unsure of what they would find when they arrived and knowing that they were unlikely to see those they left behind again. New Zealand’s national identity reflects and celebrates our origins as a nation of voyagers and migrants, a people who displayed courage, toughness and resilience as they settled in this land. As the Topp Twins movie suggests, these characteristics are found both in Kiwi males and females.

### 2.5 Theorising women’s bodies

This research project is also about bodies. It is about women’s bodies and the lives of the women who inhabit those bodies. It is about a group of women who are forced to think about their bodies in a particular way because their bodies have an increased chance of developing certain types of cancer. It is particularly about women’s bodies because ovarian cancer only affects women, and the majority of people who get breast cancer are also women. It is a study that considers the way in which an inherited predisposition to cancer, carried silently in every cell of the body, impacts on the lives of these women, on their external bodies as they consider ways to manage their risk and on their internal being and spirit as they live with this risk.

Women’s bodies have historically been the subject of much thought, writing and action. Traditionally they were thought of as the property of men, belonging first to their fathers and then to their husbands (Weitz, 1998). The historically male dominated medical profession supported these beliefs by providing medical “evidence” that showed that women’s bodies were different from men’s bodies in ways that made women’s bodies defective and dangerous (Weitz, 1998). Prior to about 1700 males and females were understood to be two versions of the same sex, with female bodies viewed as imperfect versions of male bodies (Holmes, 2007). Women’s reproductive organs were understood as incomplete versions of male reproductive organs, and as such, were believed to be responsible for irrational behaviour by women (Holmes, 2007; Holmes,
This belief led to the view that women’s reproductive organs were the cause of many illnesses and mental health problems, including conditions such as malaise and rebelliousness (Holmes, 2009; Weitz, 1998). The surgical removal of reproductive organs was used as a “treatment” for these conditions as it was believed that removal would “cure” these “illnesses” (Holmes, 2009; Weitz, 1998). Historical beliefs such as these are still influential in medicine today, apparent in the use of a language of deficit and decay when discussing natural life processes such as menstruation and menopause (Martin, 1994). These historical beliefs are also apparent in the biomedical model of objectification of the body with its orientation towards “fixing” parts that are “broken”. For women, this may include removal of organs such as breasts and ovaries (Broom, 1995; Young, 1990). While the feminist movement of the late 1960s and early 1970s was initially concerned with achieving equality within existing social structures, efforts were also made to reclaim women’s bodies from the medical profession. Women started to educate themselves and each other about their own bodies and to reclaim natural processes such as menstruation, childbirth and menopause from a male dominated medical profession (Boston Women’s Health Collective, 1971; Dann, 1985; Jarviluoma et al, 2003). At the same time, the objectification of women’s bodies and the maintenance of gender domination by means of certain forms of clothing and adornment such as makeup came to be seen as a political issue requiring change (Bordo, 1993).

Femininity (and masculinity) is achieved as a result of both social structures and expectations and of behaviours that produce a body that is recognisably feminine (or masculine) (Bartky, 1998). Bodies are texts of culture, symbolic forms inscribed with the prevailing historical forms of femininity (Bordo, 1993). Women work to produce a body that has a feminine shape and appearance, learning to act, move and gesture in ways that are recognisably feminine, and adorning the body in ways that conform to cultural and social norms for women (Bartky, 1998). Modern, Western societies appear to place little value on older women, with many of the women interviewed by Coward (1992) for her book *Our Treacherous Hearts* fearing the loss of desirability that they saw as being part of the aging process. Youthfulness and slimness are two aspects of femininity that appear to be viewed as central to maintaining an appropriately feminine look (Coward, 1992; De Francisco & Palczewski, 2007) with women reporting that the changes that occur as they reach menopause, as it becomes more difficult to maintain a body that is suitably feminine, are distressing (Coward, 1992; Darke, 1996; Dillaway,
In her study of women’s experiences of menopause, Darke (1996) found that physical attractiveness to men was fundamental to these women’s perceptions of femininity. They all disliked putting on weight at menopause because they believed this altered their femininity. Whelehan (1995) suggested that all women understand the value that is placed on a woman’s appearance, although many women don’t personally see their own value as being directly attributable to physical attractiveness.

The focus on physical attractiveness to men is apparent in much of the writing about women’s bodies. According to Coward (1992) women want those things that they have traditionally had; children, family and “the confidence of being found sexually attractive by men” (p. 1.). Breasts are a visible, tangible signifier of femininity, perhaps the most important symbol of female sexuality (Young, 1998). To be a woman is to have breasts – two of them. Many hundreds of women undergo treatment for breast cancer each year, involving removal of part or all of a breast. Yet how often do we see a woman venturing out without prosthesis, exposing the effects of her treatment and the evidence of her disease to the public eye? Young (1998) suggests that it is the way that breasts look that matters, particularly for men. For women it is the feeling and sensitivity of their breasts that is more likely to be important, with Young (1998, p. 127-8) pointing out that for “many women breasts are a multiple and fluid zone of deep pleasure quite independent of intercourse, though sometimes not independent of orgasm”. That women are prepared to undergo surgery to remove their still-healthy breasts, to lose these zones of deep pleasure, often in order to fulfil their familial responsibilities, demonstrates courage and resilience, and perhaps also a deeply felt social responsibility.

The desire to nurture and care for others, to put the needs of others before themselves, is a desire that is socially constructed and is viewed as natural. It is so deeply entrenched a belief for many women that it goes unnoticed and un-reflected upon. As Bordo (1993) writes, culture casts women as the emotional and physical nurturers. Women are taught to experience desires for self-nurturance as greedy and excessive, resulting in the development of a totally other-oriented focus (Bordo, 1993). This other-oriented economy may result in women neglecting their own health and well-being to care for their families. For example, in a study exploring the experiences of obese women, Warin and colleagues (2008) found that these women put the needs of their children and partners ahead of their own need for regular exercise. Women have also reported feeling guilty for trying to meet their personal needs even after their children are adults and...
have left home (Dillaway, 2006). Studies exploring the social aspect of sleep also show that women subvert their own need for sleep in order to care for children and partners through the night (Hislop & Arber, 2003a; Hislop & Arber, 2003b; Kirkman, 2010; Venn et al, 2008).

Barnes & Murphy (2009) argue that motherhood is a socially valued identity. Women have historically been placed at the centre of family life, providing care for children and for elderly or ill family members. Ideologies surrounding mothering reach deep into women’s lives, shaping their identities and meaning that all mothers can tell you what it means to be a “good” mother (Dillaway, 2006). Women’s bodies are intimately involved in the processes involved in becoming a mother. Once the child is born, women use their bodies to feed, nurture and protect their child. It is in the act of breastfeeding that the tensions between breasts as sexual objects and breasts as a source of nurturance for others collide. In introducing her book on the history of the breast, Marilyn Yalom (1997) reminds us that breasts are “sexual ornaments – the crown jewels of femininity” (p. 3). Women in Western cultures display their breasts as part of their appearance work (Stearns, 1999), as a visible signifier of their femininity, and perhaps also their sexuality. Breasts are, at the same time, signifiers of nurturance, a source of maternal love and care. Breastfeeding has been reported as challenging in a society that sexualises the breast (Murphy, 1999; Stearns, 1999; Young, 1998), but there is also writing that describes the pleasure and satisfaction women receive from using their bodies to nurture their children (Yalom, 1997).

This discussion has so far concentrated on the external body. Bodies also have interiors, myriads of internal organs and cells, working silently to keep the body functioning. For women who carry an inherited predisposition to developing cancer, the interior of their body and the possibility of cellular changes that may result in cancer become a preoccupation. These women carry an awareness of the inside of their bodies. This concern with the interior body is also found in women who have had cancer. In a study exploring the experience of mastectomy, Crouch and McKenzie (2000) found that a concern with the internal workings of the body and the possibility of cellular changes resulting in a recurrence of breast cancer resulted in significant fear for these women. The invisible interior body becoming heard, or visible, has also been noted in a study of women who have had cervical changes. Blomberg and colleagues (2009) interviewed a group of women after an abnormal Pap smear and found that these women reported a
change from a body which they could take for granted to a corporeal body which has made itself “heard”. For these women, a previously hidden, invisible and “silent” part of their feminine body has been brought into their awareness through the finding of abnormal cells and the resulting recommendations for further tests and treatment.

2.6 Sexuality

Sexuality is a complex and subjective concept. Whelehan (1995) suggests that there is significant difficulty in determining what is meant by the word sexuality, with the breadth and scope of the use of the term making it meaningless. It is a pervasive aspect of our total self, encompassing thoughts, emotions, desires, sensations, acts and identities (Moloney & Kirkman, 2005). Sexuality includes our sexual responses, roles and relationships (Pelusi, 2006). Whelehan (1995) suggests that we might regard sexuality as a social presence “bringing together the capacity to reproduce, desire, and need, fantasy, gender identity and bodily differences” (p. 151). Theorists such as Jeffrey Weeks and Michel Foucault have suggested that sexuality is “bounded and defined by social and cultural meanings” (Whelehan, 1995, p. 165), a theory that feminist theorists have also embraced. Assuming a broad definition of human sexuality allows us to explore the meanings of being at increased risk for these women as they consider issues related to their roles and identities as women, mothers and partners, alongside issues related to the ways that they feel about their bodies and their intimate relationships.

As Jackson and Scott (2010) say, sexuality is an ordinary part of everyday life for most people. It is one aspect of the way that we live our lives. Jackson and Scott argue that the study of sexuality should include this everyday sexuality and the “ordinary, everyday negotiation of conventional sexual lives” (2010, p. 162). They go on to comment on the importance of the local, with most people conducting their sexual lives within their own local context. In a study considering sexuality in New Zealand, one must consider the influence of our social and cultural history on the way in which New Zealanders understand and practice sexuality. Pat Moloney and Allison Kirkman (2005) suggest that sexuality is a contested issue in New Zealand, with several competing discourses influencing the way that we think about sexuality. New Zealand presents itself as a democratic nation standing independently here at the bottom of the world. New Zealanders pride themselves on taking a stand about issues that have world-
influence, such as the nuclear-free New Zealand stance. With regard to sexuality, the New Zealand government has passed ground-breaking legislation such as the Homosexual Law Reform Act (1986) and The Prostitution Law Reform Act (2004); legislation that perhaps suggests a liberal approach to sexuality. However, many New Zealanders remain uncomfortable talking about their sexual lives. This unease is manifest in things such as New Zealand having one of the highest rates of teenage pregnancy among OECD countries (Dickson et al, 2000; Nash, 2001).

Masculinity and femininity have been constructed in New Zealand in ways that have given men certain rights and expectations in their sexual lives. For example, Jan Jordan’s (2004, 2005) work about rape in New Zealand highlights masculine assumptions regarding their right to sexual expression. Women have only recently begun to assume the same rights to sexual autonomy and Moloney & Kirkman (2005) indicate that there is still a way to go before true sexual equality is achieved for individual New Zealand women.

2.7 Living with an increased risk of ovarian cancer

A number of international studies have examined aspects of the experience of living with an increased risk of breast and ovarian cancer, using both qualitative and quantitative methodologies. These studies are primarily found in the social science, psychology and genetic counselling literature, with additional material in the anthropological and biomedical literature. While traditional feminist research had at its heart the assumption that open-ended explorations of women’s experiences were the only possible way of understanding how women’s worlds are organised, Maynard (2004) reminds us that enumeration in the form of quantitative research makes an important contribution to developing knowledge and understanding of women’s experiences. The lessons from the literature about living with an increased cancer risk provide a good example of the way in which valuable lessons can be learned from a variety of different types of study.

The work of British researcher Nina Hallowell provides significant insight into the experience of living with an increased risk of breast and ovarian cancer, particularly as she was one of the researchers working in this field during the period when the BRCA
genes were identified. Her work covers the period prior to the availability of clinical genetic testing for cancer predisposition and goes on to explore the implications of predictive testing. Hallowell has written extensively, and her papers include interviews with women about their perceptions of prophylactic salpingo-oophorectomy (Hallowell, 1998); interviews about women’s perceptions of prophylactic mastectomy (Hallowell, 2000) and premenopausal women’s experiences of prophylactic salpingo-oophorectomy (Hallowell & Lawton, 2002; Hallowell et al 2004). Hallowell writes about the “at risk” identity that some of these women develop and suggests that this has profound implications for their perception of their self and their body. She suggests that women come to view certain parts of their body, namely their ovaries and breasts, as “dangerous objects” or sites of risk. Two competing discourses are found in the women’s discussions about prophylactic surgery. They explore a discourse in which the body is viewed as dangerous and which may be more or less amenable to control, depending on the individual’s perception of the dangers. At the same time, they consider a discourse regarding the feminine body, in which the body is constructed as naturally gendered. In order for women to make decisions about prophylactic surgery, a process of Cartesian splitting occurs, allowing women to separate their body from their self. In the course of her work, Hallowell has written about the role both breasts and ovaries play in making a woman look and feel like a woman. Her works suggests that breasts are important in creating a visibly feminine body, while ovaries are important in making a woman feel like a woman. This work is discussed in detail in the later chapters of this thesis.

A number of other qualitative, interview based studies have explored aspects of living with an increased cancer risk. D’Agincourt-Canning (2006) reported on the responses of Canadian women and men to BRCA genetic testing results, finding that many of the respondents described the potential for developing cancer as having a profound effect on their lives. Many of the women in this study used the information to guide their management decisions; however for a few women the information had a limiting effect on their agency, leaving them feeling vulnerable and uncertain. In an Australian interview-based study examining the short and long term effects of receiving genetic test results for hereditary breast and ovarian cancer, Lim et al (2004) also found that most women reported advantages to knowing their mutation status. Knowing gave them feelings of control and a reduction in uncertainty and the women were able to use the
information to guide management choices. Feelings of control associated with knowing that one is carrying a BRCA mutation have also been reported by Kenen and colleagues (2003) who described the use of an illusion of control heuristic to guide management choices and the decision to undergo risk reducing surgery. The empowering aspects of knowledge regarding risk are reflected in the names of both the American and New Zealand support groups for women with BRCA mutations. The American group is known as FORCE, which stands for Facing Our Risk of Cancer Empowered, and the New Zealand group is called The Gift of Knowledge.

Two recent studies report on aspects of being at increased risk. Dagan and Goldblatt (2009) interviewed Israeli women who were asymptomatic BRCA mutation carriers. They described the women as living in a twilight zone between health and illness. The women in this study appeared to view the experience of carrying a BRCA mutation negatively, indicating high levels of worry and fear regarding the possibility of a cancer diagnosis. A number of the women who were in their 40s had chosen not to have pre-menopausal salpingo-oophorectomy. While some women indicated that the knowledge of the increased cancer risk was powerful in providing the option of acting on the risk, several women talked about their anxiety that they would not see their children grow up. However, they did not appear to use this fear as a motivating factor in seeking to reduce or actively monitor their risk.

In an American study, Klitzman and Chung (2009) interviewed a group that included women who had had breast cancer, asymptomatic women, women who had had genetic testing, and women who had not had testing. They reported that the women experienced facing a series of uncertainties requiring decisions, which these women found stressful. This study highlights difficulties with communication with doctors, citing problems with basic communication as well as with more sensitive issues such as sexual functioning and reproductive plans. The problems with communication highlighted by Klitzman and Chung (2009) reflect pervasive and entrenched difficulties with communication in medical care, which will be discussed in later chapters.

As the availability of genetic testing has grown, increasing numbers of young women are able to clarify their individual risk of developing breast and ovarian cancer. The emerging literature suggests that the issues for young women may be somewhat different than for women who are older when they learn about their cancer risk. Young
women are negotiating life goals regarding partners, having children and developing a career, all of which may be impacted by the finding of an increased susceptibility to cancer. Werner-Lin (2007) interviewed women aged 22-36 years and found that integrating genetic information into their life-plans was an ongoing process involving fluctuating periods of calmness and distress. Women in her study voiced concerns regarding finding a partner to care for them when they got cancer, and described experiencing pressure to have children so that they could then have risk reducing salpingo-oophorectomy. Difficulties with telling potential partners about risk reducing mastectomy were identified by women in Werner-Lin’s (2007) study. The relationship implications of living with an increased cancer risk were also explored by Hoskins et al (2008) in an interview study of young women who were unmarried at the time that they had BRCA predictive testing. These women identified a number of challenges including doubt regarding their desirability as a life partner. They looked for a partner who would feel sufficient concern so that the woman felt cared for, but who would not show so much concern as to add to the woman’s own anxiety. Hamilton and colleagues (2009) used email or phone interviews to explore the experiences of women aged 18-39 years and found that the choices they made were influenced by their life trajectories. Women who were acutely aware of their family history of cancer, and women who had lost their mother to cancer, were motivated towards risk reducing surgery because they found it difficult to trust surveillance. Collectively, these studies indicate a significant impact on many aspects of the lives of these young women, including the formation of relationships and the timing of having children. A sense of urgency to complete life goals is suggested by the need to achieve these goals prior to undergoing risk reducing surgery.

2.8 Risk management options

Risk reducing salpingo-oophorectomy and/or mastectomy are management options that are undertaken by a number of women with an increased risk of developing cancer. The experience of risk reducing mastectomy was explored by Lloyd and colleagues (2000) in a small British study involving interviews with ten women and eight of their partners. The central theme to their experiences was one of suffering and countering multiple losses. The cancer-related deaths of close relatives contributed to the decision to
undergo surgery; however these women then found that the experience of surgery re-awakened past grief. This group reported receiving little directive advice from their doctors and sought to frame the decision to have surgery as part of their responsibility as mothers, wives and daughters. Finding comfort in doing what they could to fulfil their responsibilities to their families was also reported as a central theme in the postings on the FORCE website of women undergoing risk reducing mastectomy (Kenen et al, 2007). Kenen and colleagues (2007) analysed the postings of twenty-one women over several years and found that the freedom from fear of developing cancer was worth the difficulties and losses associated with the surgery.

Feelings of being in control have been reported both in studies of the experience of genetic testing (Kenen et al, 2003; Lim et al, 2004) and in studies exploring the experience of risk reducing salpingo-oophorectomy (Hallowell & Lawton, 2002; Hallowell et al, 2004; Meiser et al, 2000) and mastectomy (Hallowell, 2000). As a group, these studies suggest that genetic testing and risk management, particularly risk reducing surgery, give women a sense of control, allowing them to move on with their lives without the fear and uncertainty that has previously been a central part of their lives. This observation supports Alaszweski and Coxon’s (2008) suggestion that risk is a resource that individuals may use as they seek to actively manage their lives.

Qualitative, interview-based studies allow an exploration of the lived experience of relatively small groups of women who have had or are considering risk reducing surgery. Surveys, questionnaires and measures of cancer related worries, psychological distress and the impact of surgery on body image provide us with information from larger numbers of participants but with less detail and opportunity to explore experiences. During 2004 Wainberg and Husted published a systematic review of the literature regarding screening and surgery choices in unaffected women who carry a BRCA mutation. They found five American and two Dutch studies, which reported that between 0 and 54% of women chose risk reducing mastectomy and between 13 and 53% of women chose risk reducing salpingo-oophorectomy. Mastectomy was associated with younger age and having children and salpingo-oophorectomy was, perhaps unsurprisingly, associated with older age. Litton and colleagues (2009) surveyed 312 women who had had BRCA testing and found that the majority (64.7%) agreed that risk reducing mastectomy was the only way to reduce worry regarding a diagnosis of breast cancer.
While these studies indicate that women appear to support the idea of both risk reducing salpingo-oophorectomy and mastectomy, studies of women after surgery indicate that the surgery has significant ongoing implications for some women. For example, Robson et al (2003) report on a questionnaire-based study of 59 women who had a risk reducing salpingo-oophorectomy between 1997 and 2000. The majority of the women surveyed were postmenopausal at the time of the surgery, with only 28% identifying themselves as pre- or perimenopausal when they had surgery. While overall quality of life was similar to that reported by the general population and by breast cancer survivors, this group of women reported that symptoms related to oestrogen deprivation, particularly vaginal dryness and dyspareunia were bothersome. Problems associated with sexual functioning were the most significant predictors of a woman’s satisfaction with the surgery. Given that one of the goals of surgery is to reduce cancer-related worry, it is concerning that 20.7% of the women in this group reported significant worries related to ovarian cancer despite the surgery.

Hopwood and colleagues (2000) conducted a study using data from a multi-disciplinary clinic which provided annual follow up to women who had had risk reducing mastectomy. Two-thirds of the women in this study reported changes that were impacting on their lives in a minor way. This included 55% of the group reporting reduced feelings of sexual attractiveness, 53% reporting feeling less physically attractive, 53% feeling self-conscious about their appearance and 34.7% feeling less feminine. While most of the women in this study reported that they were coping well after surgery, a small number experienced significant distress requiring ongoing psychological support.

In a retrospective Dutch study examining satisfaction with prophylactic mastectomy in the longer term, Bresser and colleagues (2006) found that the long-term impact on quality of life and a woman’s sexual relationship should not be underestimated. They speculate that women experience initial relief from anxiety, which may be why studies conducted within a few months of surgery show general satisfaction with the procedure. However as time goes by the women become more aware of the irreversible consequences of the surgery. In this study, Bresser and colleagues (2006) found that nearly all the women (97%) reported altered sensation in their breasts, with 51% saying that their breasts no longer felt like their own. Of note, 44% of this group reported adverse changes in their sexual relationships after surgery. In a finding that is reflected
in many of the qualitative studies, women who reported adverse changes in sexual relationships and who reported overall dissatisfaction with the surgery also reported that they did not receive adequate information prior to surgery. Hopwood and colleagues (2000) recommend that centres offering risk reducing mastectomy do so within a clinical protocol that includes long term follow up by a multi-disciplinary team that includes a social worker or psychologist, a suggestion that is also made by Lloyd et al (2000) and Bresser et al (2006). More recently Patenaude and colleagues (2008) looked at the support needs of women undergoing risk reducing bilateral mastectomy and contra-lateral risk reducing mastectomy and found widespread support for a psychological consultation both prior to and after surgery. Researchers have consistently reported the need for psychosocial input around risk reducing surgery, indicating that this is a priority for many women considering or undergoing risk reducing surgery.

2.9 Conclusion

Risk has been conceptualised as both adverse (Beck, 1992) and neutral (Austen, 2009). Regardless of the way in which risk is understood, it is clear that in this period of late modernity, individuals and communities are subject to an increasing number of potential risks. Many of these have arisen as a result of technological and scientific advances, among which is the ability to test and identify some individuals who have an inherited predisposition to developing particular types of cancer. Women who carry a mutation in a BRCA gene face a risk that directly affects the organs which are central to feminine identity. As the work of British sociologist, Nina Hallowell, has shown, these women appear to adopt an “at risk” identity and to view their breasts and ovaries as potentially dangerous objects. Concepts of risk and the effect on feminine identity are central to the work in this thesis, alongside the social and cultural understandings of the New Zealand women who participated. The following chapter situates the provision of genetic services in New Zealand, providing an overview of the genetic counselling and risk assessment process and of options for medical management of the risk.
Chapter Three
Situating Genetic Services in New Zealand

Genetic Services in New Zealand offer a comprehensive risk assessment process for families with a family history of cancer, including ovarian and breast cancer. Genetic Services is a tertiary service situated within the public health system in New Zealand. This chapter provides the background and context for the study including discussion regarding the social context of healthcare in New Zealand and the social context within which genetic services are offered, along with an explanation of genetic counselling, risk assessment, genetic testing and risk management options for hereditary breast and ovarian cancer.

3.1 Healthcare in New Zealand

Health care in New Zealand is currently organised into primary, secondary and tertiary care. Primary care involves services such as general practitioners (GPs) along with other health providers including community nurses, physiotherapists and public health services. Secondary care is hospital based and includes general medicine, general surgery, paediatric and obstetric care. Tertiary services are more specialised, hospital based services such as neonatal intensive care, specialised surgical services and genetic services. Tertiary services are based in only a small number of hospitals, located in the larger cities. In New Zealand the government is the dominant provider of hospital based services, while primary care, in particular general practice, is based on a private “fee for service” means of provision (Gauld, 2003).

The New Zealand voting public view health care as a crucial policy issue and New Zealand has consequently undergone a rapid cycle of health reforms in the past twenty years. Public dissatisfaction with these reforms has resulted in further reforms (Gauld, 2003). This has created a health care system that has been in a state of transition since the early 1980s (Gauld, 2003). The current organisation of health care delivery involves the centralised control of the health system through the Ministry of Health, which provides funding to twenty District Health Boards (DHBs). The DHB system was
introduced by a Labour-led coalition government elected in 1999, and was the final in a series of four rapid health reforms begun in the early 1980s. Ironically, the DHB system is conceptually identical to the Area Health Board system which was in place at the time of the initial reforms (Gauld, 2003).

The changes in provision of health care occurred in the wider context of significant political and ideological change in New Zealand. By the 1970s the democratic state was experiencing pressure from many interest groups outside of the official political sphere (McLennan, Ryan and Spoonley, 2000). The state could not meet the demands of these groups, financially or otherwise. As noted by Jane Kelsey (2000), New Zealand changed rapidly from being “a bastion of welfare interventionism to a liberal reformer’s paradise” (p. 166). During the early 1980s the role of the state, and the accompanying social spending, was pared right back so that the state’s principal concerns were defending the nation, maintaining basic law and order and providing minimal social security. McLennan, Ryan and Spoonley (2000) suggest that the National government of the early 1990s became the first government in the world to create a “post-welfare” society. These reforms created fissures in the political and social frameworks of New Zealand (Kelsey, 2000).

The neo-liberal reforms of the 1980s and 1990s have fostered an ideology in which individuals and families are required to take on responsibility for the provision of health care, education and welfare (Kelsey, 1997; McLennan, Ryan and Spoonley, 2000). There is an emphasis on economic rationalism, or the belief that the market is the most appropriate way to allocate resources, resulting in cuts to government responsibilities and privatisation of services. For individuals and families, this means that they are free to make their own choices, and at the same time they are required to shoulder the blame if they make the “wrong” choices. Documents such as the Code of Social and Family Responsibility, issued by the Department of Social Welfare in 1998, reinforce the message that the government has removed itself from key areas of social welfare and that the responsibility now lies with individuals and families.

Neo-liberal policies in health care include encouraging health promotion through public health campaigns. Petersen (1999) notes that these policies are often associated with encouraging individuals to take responsibility for their own health. Messages regarding the promotion of healthy lifestyles are dominant in New Zealand public health
campaigns, with significant amounts of public funding used for campaigns encouraging people to stop smoking, exercise more and maintain a healthy weight, as well as to participate in publicly funded screening for breast and cervical cancer. These campaigns, supported by public funding, deliver repeated messages about individual responsibility for health and well-being in New Zealand. Genetic Services therefore operates within a culture where discourses of individual and family responsibility dominate.

A sentinel event in the history of health care in New Zealand occurred during the mid 1980s. As the result of an article in an Auckland-based monthly magazine, a judicial inquiry into unethical practices regarding the care of women with carcinoma in situ of the cervix at the National Women’s Hospital in Auckland was conducted. This inquiry garnered widespread media attention and the resulting Cartwright Report had significant ramifications for the relationships between health care practitioners, patients and the New Zealand public (Manning, 2009; Skegg, 2009). The recommendations of the report resulted in the development of the New Zealand Code of Health and Disability Service Consumer’s Rights, a document that enshrines protections for healthcare users in legislation while at the same time outlining the rights in plain language to increase its accessibility (Manning, 2009). Healthcare in New Zealand is therefore provided in an environment where there are expectations regarding adequate communication from practitioners alongside informed consent from patients. Health practitioners are expected to respect the rights of patients to participate as partners in their care and to make choices that reflect their own world views and experiences.

3.2 Genetic Services in New Zealand

Genetic Services offer a process of risk assessment for people with a family history of cancer. In New Zealand we have two Genetic Services. The Northern Regional Genetic Service in Auckland serves the population living north of a line drawn between Taranaki and Hawkes Bay, and the Central and Southern Regional Genetic Service, which has offices in Wellington and Christchurch, covers the rest of New Zealand. Both services offer clinics in local hospitals and provide extensive and regular outreach services to regional hospitals. For example, the Central and Southern Regional Genetic Service provides monthly clinics in Dunedin and clinics are held in cities such as
Palmerston North, Napier and Nelson every second month\textsuperscript{20}. Genetic Services are a publicly funded tertiary service, with the individual District Health Boards contracting for services from the lead District Health Board. Diagnostic, predictive and prenatal genetic testing is publicly funded in New Zealand, along with some carrier testing. Families occasionally choose to pay for carrier testing for conditions where the carrier frequency is below the threshold for accessing publicly funded testing.

The Central and Southern Regional Genetic Service and the Northern Regional Genetic Service collaborate when working with shared families. Both services have links with specific disease-based registries, particularly the New Zealand Familial Gastro Intestinal Cancer Registry.

Genetic Services are staffed by Clinical Geneticists and Genetic Associates (also called genetic counsellors and referred to as genetic counsellors for the purpose of this thesis) along with support staff. Close ties with laboratories in New Zealand and overseas are maintained. Genetic counsellors have a post-graduate qualification in genetic counselling and work towards obtaining certification through the Human Genetic Society of Australasia (HGSA). A “maintenance of professional standards” programme is also offered through the Human Genetic Society of Australasia. The genetic counsellors see the majority of people referred due to a family history of cancer, with familial cancer counselling forming approximately two thirds of a New Zealand genetic counsellor’s workload.

Genetic Services receives referrals from a number of sources including general practitioners, breast surgeons, gynaecologists, oncologists and other medical professionals. When a family is known to the service, as with families where a mutation has been identified, self-referrals from family members wanting to discuss predictive testing are accepted. Referrals depend on the individual’s medical practitioner taking a family history and identifying features of a familial cancer syndrome. Both the Central and Southern Regional Genetic Service and the Northern Regional Genetic Service have waiting lists, reflecting an increasing demand for familial cancer risk assessment resulting from both an increased public awareness and increased levels of requests from medical professionals (Hodgson et al, 2007). People are triaged onto the waiting list for the clinic nearest to their home. Waiting times vary from one to twelve months

\textsuperscript{20} Please see appendix 4 for a map of New Zealand which includes these locations.
depending on the location of the clinic. Referrals are triaged based on clinical urgency and genetic counsellors regularly contact families by phone and in writing in the case of urgent referrals. People who are having treatment for cancer are offered the option of combining another appointment with their genetic clinic appointment, so the genetic counsellors will sometimes see people while they are attending for chemotherapy or while they are inpatients. Home visits are very rarely offered due to limited staff numbers.

3.3 The process of cancer genetic counselling

Individuals and families come to an appointment with Genetic Services for several reasons. In the case of a family that has not been previously assessed, they may come requesting an initial assessment of their family history of cancer. The process for these families involves a full assessment of the family history and an offer of genetic testing if the family meets certain criteria (discussed below). If genetic testing is offered, it will involve a full mutation search. In families where the genetic cause of the cancer predisposition has been identified, individual family members may come to Genetic Services seeking a predictive test. A predictive test is used when a mutation has been identified in the family and an individual wishes to know whether or not they have inherited it.

Cancer genetic counselling involves an exchange of information between the client and the genetic counsellor. The interaction should offer the client the opportunity to explore the meaning of the cancer diagnoses in the family and the meaning of the risk assessment. In a best practice situation, there will be a number of distinct components to a cancer genetic counselling session, including contracting, collecting and interpreting the family history, describing the cancer syndrome, providing a risk assessment, discussing surveillance, and discussing genetic testing options (Schneider, 2002). In the reality of a busy clinic, particularly in outreach settings where long waiting lists often mean that clients are given forty-five minute appointments rather than an hour, the components of the session are likely to be present but may be condensed so that the focus of the discussion is on the matters that are most pertinent to the individual.
Contracting takes place during the initial moments of a meeting with a client. The scene is set for the meeting and the expectations of the client and counsellor discussed (Schneider, 2002). The genetic counsellor’s tasks are to listen to the client’s goals, communicate their own goals for the session, assess the client’s motivation and set the tone for the visit (Schneider, 2002). It is important that clients begin to feel comfortable during the initial moments of a genetic counselling session, so that they feel safe to talk about their personal and family histories (Schneider, 2002; Weil, 2000).

Providing accurate genetic counselling is dependent on gathering accurate and detailed information (Schuette & Bennett, 1998). The family history is used as the basis for assessing the family, determining the possibility of a cancer susceptibility syndrome and providing a risk assessment (Schuette & Bennett, 1998). Clients come to genetic counselling with varying levels of information about their family history. There are a number of different ways of collecting the family history. Some services prefer to collect this information prior to meeting with clients and to review the information for completeness during the meeting, while other services collect the family information during the meeting (Schneider, 2002). In New Zealand Genetic Services send a family history questionnaire and consent forms when a referral is received, and about half of these are returned prior to the appointment. Cancer diagnoses are verified through the New Zealand Cancer Registry, with written consent from the individual concerned or from next of kin if the individual is deceased. The identification of a family cancer syndrome is a family issue and therefore it is vital that genetic counsellors working with families understand the communication patterns and interactions within each family (Weil, 2000). Genetic counsellors often gain valuable insights about family dynamics and the impact of cancer on the family while drawing a family tree. Schneider (2002) mentions the importance of allowing clients to weave anecdotes about individuals into their stories, thus ensuring that affected individuals are seen as people rather than cases.

Clients differ in their understanding of the family history. Some clients have long suspected a hereditary basis to the cancer in the family, whereas this idea may come as a complete surprise to others (Schneider, 2002). Schneider (2002) suggests that a genetic counselling discussion include a description of the name and features of the suspected cancer syndrome, information about the tumours associated with the syndrome, typical ages of onset and the mode of inheritance. Genetic counsellors learn to adapt the
discussion to the client’s educational level and adjust the amount of detail to suit individuals (Schneider, 2002).

Many clients come to genetic counselling requesting an assessment of their own or their family’s risk of developing cancer. Presenting risk estimates in cancer genetic counselling is a challenging task as there are inherent uncertainties in the currently available risk figures (Schneider, 2002). For example, the risk of developing different types of cancer associated with specific cancer syndromes changes with ongoing research. Clients are faced with a complex set of probability figures relevant to their cancer risk so the genetic counsellor needs to be able to provide a conceptual framework to help with understanding the risk figures and guidance regarding the relationships between the different figures (Weil, 2000).

A discussion about cancer surveillance and risk reduction options is a crucial part of cancer genetic counselling as many clients come to the genetic clinic requesting information about what they can do about their risk. The purpose of surveillance is to detect signs of cancer at an earlier, and therefore potentially more curable, stage (Schneider, 2002). Discussing management recommendations often provides an opportunity to explore the client’s concerns about developing cancer and their coping mechanisms for managing the risk (Schneider, 2002).

The option of genetic testing is available to some families. During the initial discussion about genetic testing the counsellor’s tasks include determining the client’s interest in testing, providing information about the testing process, describing possible results, exploring the advantages and disadvantages of testing, and discussing the possibility of insurance discrimination (Schneider, 2002; Weil, 2000). The ability to provide genetic testing for some hereditary cancer syndromes has lead to a change in understanding of genetic testing and the emergence of new emotional issues and responses (Weil, 2000). Clients may believe that genetic testing is a straightforward process that will resolve issues of uncertainty and decisions about surveillance or prophylactic surgery (Weil, 2000). Genetic counsellors try to explore the client’s expectations and explain that there is a strong possibility that a mutation will not be identified and that testing may not clarify these issues.
After an appointment, the genetic counsellor almost always writes a letter to the client, summarising the discussion and providing written details of the family history, risk assessment and surveillance guidelines. With the client’s permission, a copy of this letter is sent to the referring doctor, the client’s general practitioner, and any specialists that are involved in their care. When a mutation is identified in an individual, genetic counsellors offer to provide a more general “family letter” to help the client inform their extended family of the presence of the mutation in the family. Summary letters written by genetic counsellors provide families with a valuable education resource regarding the risk assessment and subsequent recommendations (Baker et al, 2002; Smith, 1998) and it is common to have clients talk about reading letters that other family members have received. Genetic counsellors in Australasia, North America and the United Kingdom receive training in letter writing and guidelines for these letters exist (Baker et al, 2002).

3.4 Risk assessment for hereditary breast and ovarian cancer

The risk assessment involves collection of a detailed three or more generation family history and collection of histological records about as many cancers in the family as possible. BRCA1 or BRCA2-related hereditary cancer is suspected in individuals with a family history of breast cancer or breast and ovarian cancer which is consistent with autosomal dominant inheritance. Other features of the family history may include early age of onset of cancers, bilateral or multi-focal disease in an individual, male breast cancer and Ashkenazi Jewish ancestry (McIntyre et al, 2002). In New Zealand, families are given a risk assessment based on National Breast and Ovarian Cancer Centre criteria (2011).

As noted above, the medical records of consenting family members who have had cancer are accessed to determine the specific type of ovarian or breast cancer that they had. This is particularly important in the case of ovarian tumours because specific histological types of ovarian cancers are associated with BRCA mutations. The majority of primary ovarian tumours arise in the surface epithelium of the ovary, including the serous ovarian tumours which are common in women with BRCA mutations. Ovarian tumours can also develop in the germ cells and the sex-cord stroma, but these tumours
are not thought to be associated with BRCA mutations.

Once the family history and histological information have been collected, a risk prediction model may be used to help predict the chance that an individual carries a mutation in a BRCA gene. A number of these models are available, including BRCAPRO, BOADICEA and the Manchester scoring system. Genetic Services’ may use one or more of these tools to help identify those families in which BRCA testing is more likely to provide an informative result (Domchek et al, 2003). The early models were based on data from a limited number of families, many of whom had a family history of breast but not ovarian cancer, so they were of limited use in the clinical setting. Subsequent models include ovarian cancer, and increasingly cancers such as pancreatic cancer are also included. The Central and Southern Regional Genetic Service primarily uses a tool called BRCAPRO, which uses published BRCA1 and BRCA2 mutation frequencies, cancer penetrance in mutation carriers, cancer status and the age of the proband’s first and second degree affected and unaffected relatives to provide an estimate of the likelihood of finding a BRCA mutation in the family. Specific computer software (Cancer Gene) is necessary to use BRCAPRO, and can be obtained free of charge from the internet. When BRCAPRO data is included as part of the risk assessment there is a slight improvement in genetic counsellor performance, so it is worthwhile incorporating this information into the risk assessment (Euhus et al, 2002).

Two other tools are also occasionally used by the Central and Southern Regional Genetic Service. The Manchester scoring system is a paper-based calculation that can be done during the clinic. Scores based on the type of cancer (including breast, ovarian, prostate and pancreatic cancers) and age at diagnosis are given for each affected family member. The final score gives the likelihood of identifying a BRCA1 or BRCA2 mutation. BOADICEA is a web-based programme that returns the predicted probability of a family carrying a BRCA mutation, lifetime risks of developing breast and ovarian cancer for unaffected relatives, and the risk of contra-lateral breast cancer and ovarian cancer for women who have had breast cancer. The most recent version of BOADICEA incorporates the risks of male breast cancer, prostate cancer and pancreatic cancer

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21 The proband is the affected family member, with the family often identified through this individual.
(Antoniou et al, 2008). BOADICEA is more difficult to use than BRCAPRO and is not routinely used by the Central and Southern Regional Genetic Service.

In clinical practice, genetic counsellors and clinical geneticists review family histories, histology information and data from one or more of the mutation prediction models outlined above in order to finalise the risk assessment and make a decision regarding genetic testing for the family. Internationally, affected individuals who are predicted to have a 10-20% or greater chance of carrying a mutation are offered genetic testing. In New Zealand BRCA mutation analysis is offered to individuals predicted to have a 20% or greater chance of a mutation. This cut-off was chosen in accordance with both international practices and budgetary restraints.

3.5 Genetic testing for hereditary breast and ovarian cancer

Two genes are known to be associated with familial breast and ovarian cancer, called BRCA1 and BRCA2. Observations of familial clustering of ovarian cancer alone and of breast and ovarian cancer among close relatives led to the identification of these cancer susceptibility genes. BRCA1 (breast cancer gene 1) was identified in 1994, and BRCA2 was identified soon after (Miki et al, 1994; Wooster et al, 1994).

Another group of genes, called the mismatch repair genes, are associated with a familial cancer syndrome called Lynch syndrome or Hereditary Non Polyposis Colorectal Cancer (HNPCC). Individuals with Lynch syndrome have an increased chance of developing colorectal, endometrial and ovarian cancers, hence the inclusion of a small number of women with Lynch syndrome in this study. These genes and their effects will be discussed in more detail below.

Genetic testing for familial cancer genes has been clinically available to New Zealanders for over ten years, starting in 1999. The initial families to be offered testing had been assessed over several years prior to 1999 and a waiting list (of families) kept. In some cases, a DNA sample from an affected family member was collected and stored. When testing became available, the families received a letter offering testing.
Testing for the two genes associated with familial breast and ovarian cancer (BRCA1 and BRCA2) and the genes associated with familial colorectal, uterine and ovarian cancer (MLH1, MSH2, MSH6 and PMS2) are currently done in laboratories in Australia. An initial mutation search costs NZD$2500-$3000 depending on the genes involved and a predictive test for a mutation previously identified in an affected family member costs approximately NZD$250-$300. The initial mutation searches used to take up to twelve months but improved technology has seen this gradually reduce so that a result is usually received within six months. If a mutation is identified, the laboratory requests a second blood sample to confirm the finding. Predictive test results take two-three months, and again, two samples are sent. The DNA is extracted in laboratories in Wellington, Christchurch or Auckland before being shipped to Australia for testing. Blood samples are collected locally and shipped to the laboratories for DNA extraction so people do not have to travel to have their blood test.

Genetic testing for mutations in the BRCA1 and BRCA2 genes must start with a DNA sample from an affected family member. The initial mutation screen includes sequencing BRCA1 and BRCA2 and screening for larger deletions or duplications. There are three possible results from the initial BRCA mutation analysis. In a minority of families a deleterious mutation in either BRCA1 or BRCA2 is identified. The majority of families receive inconclusive test results, with no mutation identified. In a small number of families an unclassified variant is identified. Unclassified variants are changes in the gene, the effects of which are not currently understood. In practice, the identification of an unclassified variant is similar to not finding a mutation as these alterations in the gene are not able to be used for predictive testing by other family members.

The identification of a mutation in a family member who has cancer offers other family members the option of predictive testing and a clearer basis for estimating disease risk. Information about mutation status is also useful for family members who have already had cancer to plan ongoing surveillance, as they are at significantly increased risk of developing a second tumour (Easton et al, 1995). Results from predictive testing can be used to develop individual risk reduction plans. In families where the testing is inconclusive, with either an unclassified variant or no mutation identified, all the
women in the family are considered to have a high risk of developing ovarian and/or breast cancer. In these families the surveillance recommendations are given based on the cancer diagnoses in the family.

BRCA1 and BRCA2 are two of a group of genes known as tumour suppressor genes. They are believed to have a caretaker role in the human genome. When they are functioning correctly, they work to protect against the development of certain types of cancer. Cancer susceptibility arises from the inheritance of a mutation in either BRCA1 or BRCA2. The development of cancer occurs after a second, sporadic mutation occurs, resulting in complete inactivation of the gene (Haber, 2002). BRCA1 and BRCA2 are involved in maintaining genomic integrity and in the DNA repair process (Tavtigian et al, 1996). When this function is lost, it allows for the accumulation of other genetic mutations, which are ultimately responsible for cancer formation (Zhang, Tombline & Weber, 1998).

Hundreds of different mutations have been identified in BRCA1 and BRCA2. A small number of mutations have been found repeatedly in unrelated families; however, the majority of the mutations have only been reported in one or a few families (Shattuck-Eidens et al, 1997). The frequency of specific mutations is higher among a small number of ethnic groups. These “founder mutations” are found in the Ashkenazi Jewish population, Icelanders, French Canadians and a small number of other groups. Individuals who trace their ancestry to one of these groups can be offered genetic testing for a specific panel of mutations. However, most mutations are specific to one or a few families, which in part accounts for the length of time that the initial genetic testing takes.

3.6 Cancer risks associated with BRCA mutations

The BRCA genes were originally identified in 1994 and 1995, using very high risk families who were ascertained through the presence of multiple affected individuals (Begg, 2002). A large number of studies have reported the lifetime risks of developing breast and ovarian cancer for women who carry a mutation in a BRCA gene (for
example Antoniou et al 2003; Brose et al, 2002; Chen et al, 2006; Ford et al, 1998). These studies used different methods to identify families and have reported varying lifetime risks for developing cancer. While individuals who carry mutations in these genes have a high chance of developing cancer during their lifetime, it is important to remember that the risk is not absolute (Ang & Garber, 2001).

The current practice of the Central and Southern Regional Genetic Service is to quote a range of figures, rather than a specific figure. Women who carry a BRCA1 or BRCA2 mutation are given figures of 50-85% for developing breast cancer and 20-40% for developing ovarian cancer. These figures are based on studies by Antoniou et al (2003), Chen et al (2006) and Suthers (2007). Antoniou et al (2003) completed a meta-analysis of twenty-two studies of breast and ovarian cancer risks associated with BRCA1 and BRCA2 mutations where the patients were unselected for family history. In a finding that is particularly useful for genetic counsellors and surgeons working with women with BRCA mutations, Chen et al (2006) report a decrease in the relative risk of breast cancer with age. Suthers (2007) used the data from Chen et al (2006) and combined it with Australian baseline incidence data to provide estimates of both short-term and long-term risks for Australian women with BRCA mutations. This study reports that Australian women with BRCA1 or BRCA2 mutations have a cumulative lifetime risk of developing breast cancer of 50-60% and a risk of ovarian cancer of 20-40%. The data is broken down to provide graphs that show the risks in ten year periods, providing a very useful tool for genetic counselling with these women. Both Suthers (2007) and Chen et al (2006) show that the chance of developing breast cancer is higher in younger women and approaches the population risk by age sixty, whereas the chance of developing ovarian cancer continues to increase throughout a woman’s life. Irrespective of the specific risks reported by these studies, the fact remains that women who carry a mutation in a BRCA gene have a very high chance of developing breast and ovarian cancer in comparison with women in the general population.

Women who carry a BRCA mutation and have had a diagnosis of breast cancer have an increased chance of developing a second breast cancer. The chance of a second primary breast cancer has been reported to be in the order of 40% by the age of seventy years (Brose et al, 2002).
The association between germline BRCA mutations and cancers at other sites is less clear than the association with breast and ovarian cancer. A study by the Breast Cancer Linkage Consortium (2002) has suggested that BRCA1 mutation carriers are at statistically significant increased risk for pancreatic cancer and cancer of the uterine body and cervix. A number of different cancers have been observed in BRCA2 families, including cancers of the larynx, oesophagus, colon, stomach, gallbladder, bile duct and pancreas, as well as melanomas (Breast Cancer Linkage Consortium, 1999). Men who carry a BRCA mutation have an increased risk of developing prostate and breast cancer.

3.7 Medical management for women who carry a BRCA mutation

The knowledge that an individual carries a cancer-predisposing mutation provides the opportunity to engage in regular surveillance or to undergo risk reducing surgery. The purpose of surveillance is to detect cancer at an early and more readily treatable stage, while the purpose of surgery is to reduce the risk of developing cancer by removing the at-risk body parts. Women and families may regard the knowledge of their mutation status as a means of controlling their chance of developing a disease that has affected the lives of other family members. Support groups for women and families with BRCA mutations indicate the way that this knowledge may be viewed as empowering. For example, a banner heading on the New Zealand Gift of Knowledge website says “Knowledge is control. Not total control, but so much more than feeling helpless” (Gift of Knowledge, 2010). The name of the American group, Facing Our Risk of Cancer Empowered, also harnesses the notion of information as empowering.

Women who carry BRCA mutations have the option of regular surveillance aimed at the early detection of breast and/or ovarian cancer, risk reducing surgery or a combination of both surgery and surveillance. The medical options are most well-defined for women known to carry a deleterious BRCA mutation. The medical options are similar for women with a strong family history but without an identifiable BRCA mutation, but the decisions may be more complex as these women do not know whether they have inherited the familial risk or not. As noted by Hallowell (1999a), the option of “doing nothing” is not usually discussed with women who attend genetic counselling because
of a family history of breast and/or ovarian cancer, but choosing not to pursue medical management of their risk is also an option for these women.

Options for medical management of the risk have been available for a number of years, including prior to the discovery of the BRCA genes. In the years following the identification of these genes, a number of studies have been undertaken to evaluate the effectiveness of the various methods of surveillance and risk reducing surgery (for example Casey et al, 2005; Hartmann et al, 2001; Kauff et al, 2002; Kriege et al, 2004; Kuhl et al, 2000; Meijers-Heijboer et al, 2001; Narod et al, 2001; Rebbeck et al, 1999; Rebbeck et al, 2002; Rebbeck et al, 2009; Warner et al, 2001; Warner et al, 2004;).

Options for chemoprevention of the cancer risk are also being explored (Esserman & Kaklamani, 2010; Metcalfe et al, 2004; Vogel et al, 2010). Trials of Tamoxifen and Raloxifene in women with an increased risk of developing breast cancer have found that these oestrogen modulators have a protective effect (Vogel et al, 2010) and an earlier study showed that Tamoxifen reduced the chance of developing contra-lateral breast cancer (Metcalf et al, 2004). However Narod (2010) comments that few unaffected women at high risk choose Tamoxifen as a risk reducing option, perhaps because of the potential side effects.

Research into the possibility of targeted treatment for those women with BRCA mutations who do develop breast or ovarian cancer is underway (Byrski et al, 2010; Fong et al, 2009; Tutt et al, 2010). Both the effectiveness of existing chemotherapeutic agents (Byrski et al, 2010) and the development of agents that specifically target the underlying genetic defect (Fong et al, 2009; Tutt et al, 2010) are being examined. These studies offer hope for the future for women who carry BRCA mutations.

3.7.1 Surveillance for ovarian cancer

Ovarian cancer is one of the more common malignancies among women (DePasquale, Giordano & Donnenfeld, 1998) with a frequency in New Zealand women of approximately 1.6%. It is predominantly a disease of perimenopausal and
postmenopausal women (DePasquale, Giordano & Donnenfeld, 1998). A number of different risk factors have been associated with the development of ovarian cancer, including age, reproductive history, fertility drugs and a family history of the disease. Women who have had breast cancer may also have an increased risk of developing ovarian cancer, because they carry an inherited BRCA mutation and/or because some of the reproductive factors that are associated with an increased risk of ovarian cancer may also increase breast cancer risk (for example early menarche, late menopause and nulliparity).

Surveillance aimed at the early detection of ovarian cancer has proved to be very difficult. Ovarian cancer screening involves annual (or more frequent) measurement of a tumour marker called CA-125 and examination of the ovaries using trans-vaginal ultrasound (Paley, 2001). A number of studies have evaluated the efficacy of these methods of detection and have found that they are not effective in detecting early ovarian cancer in high risk women (Cannistra, 2004). This may in part be due to the fact that the serous ovarian cancers most often found in BRCA mutation carriers appear to have a rapid progression to malignancy. The number of occult ovarian and fallopian tube cancers detected during risk reducing salpingo-oophorectomy, often after a woman has had a normal CA-125 and ultrasound prior to surgery, add to the evidence against the use of these screening options in high risk women (Finch et al, 2006; Laki et al, 2007). The United States based National Comprehensive Cancer Network suggests that premenopausal women who have not yet had salpingo-oophorectomy should be offered trans-vaginal ultrasound and CA-125 measurements in the years prior to surgery (Daly et al, 2010).

3.7.2 Risk reducing salpingo-oophorectomy

Women with an increased risk of ovarian cancer are strongly recommended to undergo risk reducing bilateral salpingo-oophorectomy (removal of the ovaries and fallopian tubes) after child-bearing is complete and by the age of about forty years (Daly et al, 2010; Domchek et al, 2010; Haber, 2002). Several studies have reported that, based on pathological evidence collected after salpingo-oophorectomy in high risk women, up to
85% of ovarian cancers may in fact arise in the fallopian tube rather than the ovary (Callahan et al, 2007; Crum et al, 2007; Finch et al 2006; Kauff et al, 2002; Paley et al, 2001). Laparoscopic salpingo-oophorectomy is now considered to be a relatively low-risk surgical procedure and is usually done as day surgery (Esserman & Kaklamani, 2010). In addition, risk reducing salpingo-oophorectomy before the age of 50 years has been shown to significantly decrease (by approximately 50%) the breast cancer risk in women with BRCA mutations (Domchek et al, 2010; Kauff et al, 2002; Rebbeck et al, 1999).

Rebbeck and colleagues (2009) have recently completed a meta-analysis of risk reduction estimates associated with salpingo-oophorectomy in BRCA1 and BRCA2 mutation carriers. They suggest that the findings from this meta-analysis be used to provide guidance to women who carry BRCA mutations when planning their management. Using data from 10 studies investigating breast or ovarian cancer outcomes after salpingo-oophorectomy, they found that removal of the ovaries and fallopian tubes is strongly associated with reductions in ovarian, fallopian tube and breast cancer risk. The authors note that a number of questions regarding the timing of surgery, the use of hormone replacement therapy, the effect of age at surgery, and the gene-specific differences in risk reduction remain.

There is a possibility that a woman undergoing risk reducing salpingo-oophorectomy will receive a diagnosis of cancer as a result of the surgery or during the subsequent pathological examination (Finch et al, 2006). Studies have found that approximately 5% of BRCA mutation carriers undergoing salpingo-oophorectomy are found to have an occult fallopian tube or ovarian cancer (Callahan et al, 2007; Finch et al, 2006; Laki et al, 2007). These studies all note the importance of rigorous surgical and pathological examination so as not to miss an early malignancy, indicating the importance of surgeons and pathologists adhering to emerging guidelines for risk reducing salpingo-oophorectomy in women who carry a BRCA mutation.

It is important that women undergoing risk reducing salpingo-oophorectomy understand that the surgery reduces but does not completely eliminate their chance of developing cancer. There is a residual risk of developing peritoneal cancer of approximately 1% after surgery (Kauff et al, 2002; Rebbeck et al, 2002).
While risk reducing salpingo-oophorectomy may be a relatively straight-forward surgical procedure and the effectiveness in reducing the risk of both ovarian and breast cancer, and indeed in reducing mortality, is now well-documented (Domchek et al, 2010, Kauff et al, 2002; Rebbeck et al, 1999; Rebbeck et al, 2002; Rebbeck et al, 2009), the potential side effects of premenopausal salpingo-oophorectomy may be more troubling. Surgical removal of the ovaries results in a rapid reduction in oestrogen and progesterone levels, in comparison with the gradual reduction that occurs during natural menopause. There is significant variation in the effect on individual women; however symptoms may include climacteric symptoms (“hot flushes” and night sweats), loss of libido, vaginal dryness and pain with intercourse, sleep disturbance, mood changes, and cognitive changes such as forgetfulness and loss of concentration. In the longer term, women who experience an early surgical menopause are at increased risk of bone loss (osteoporosis), altered bladder function and an increased risk of cardiovascular disease.

The use of hormone replacement therapy (HRT) can mitigate the climacteric symptoms of menopause and help to prevent conditions such as osteoporosis; however hormone replacement therapy has been shown to increase breast cancer risk and is contra-indicated in women who have had breast cancer (Chlebowski et al, 2010). Rebbeck and colleagues (2005) reported that short-term use of hormone replacement therapy after premenopausal salpingo-oophorectomy does not negate the protective effect of the surgery on subsequent breast cancer risk. This study has limited power due to small sample size but provides the best evidence to date related to the use of hormone replacement therapy by BRCA mutation carriers.

Hormone replacement therapy may not always mitigate the side effects of surgical menopause. Hallowell et al (2004) reported that a number of women in their study of the experiences of undergoing premenopausal salpingo-oophorectomy could not completely control menopausal symptoms using hormone replacement therapy. Madalinska et al (2006) undertook a questionnaire based study on the endocrine symptoms and sexual functioning of four hundred and fifty premenopausal, high risk women. They concluded that, while hormone replacement therapy has a positive effect on vasomotor symptoms in women undergoing premenopausal salpingo-oophorectomy, the effect may be less than is often assumed. The symptoms remained well above those
of premenopausal women having surveillance for ovarian cancer and sexual discomfort was not relieved by the use of hormone replacement therapy. They recommended that doctors provide women considering risk reducing salpingo-oophorectomy with realistic information about premature menopause and hormone replacement therapy. The Society of Gynecologic Oncologists’ (2005) clinical practice statement suggested that decisions regarding hormone replacement therapy after surgery should be individualised depending on a woman’s symptoms. They recommended that women undergo an assessment of cardiovascular risk and osteoporosis risk, with long term treatment to minimise the risk of these diseases if indicated.

Lifestyle factors and treatments other than hormone replacement therapy can be used to reduce the risk of bone loss and osteoporosis. Lappe and Tinley (1998) recommend women undergoing premenopausal salpingo-oophorectomy have a diet high in calcium and vitamin D, do regular weight bearing exercise (walking or running), maintain an optimum body weight and avoid excessive alcohol intake and smoking to help reduce the long term risk of osteoporosis. Bone sparing medications such as calcitonin, bisphosphonates and selective oestrogen receptor modulators such as Raloxifene all have a role in reducing bone loss (Lappe and Tinley, 1998).

In clinical practice in New Zealand, some gynaecologists offer women planning a premenopausal bilateral salpingo-oophorectomy the option of having a hysterectomy as part of the surgery, to increase their options for managing menopausal symptoms after the surgery. Casey et al (2005) suggest that surgery for women undergoing risk reducing salpingo-oophorectomy should include removal of the uterus along with the complete fallopian tubes and ovaries. This makes the use of Tamoxifen in women who have had breast cancer safer (Tamoxifen use is associated with an increased risk of endometrial cancer) and simplifies decisions about hormone replacement therapy, meaning that women can take oestrogen alone in doses low enough not to increase their breast cancer risk but at the same time providing sufficient oestrogen to maintain bone integrity.

### 3.7.3 Surveillance for breast cancer

Screening tests are medical tests used to look for early signs of cancer development. Breast screening, using mammography, is available in New Zealand though a publicly-
funded programme called Breastscreen Aotearoa. Two-yearly mammograms are available for all women aged forty-five to sixty-nine years. The theory behind screening programmes such as this is that one takes a population and performs a test that identifies a group of women with changes in their breast tissue who are then offered further, more invasive diagnostic testing. Women who carry a BRCA mutation are already known to have a high chance of developing breast cancer and therefore routine screening is not suitable for them. Instead, they are offered more intensive surveillance with an increased frequency of imaging tests.

Surveillance for women who carry a BRCA mutation includes six-monthly clinical breast examination and annual mammography beginning ten years younger than the earliest diagnosis in the family, or from age twenty-five years, whichever is earliest. Magnetic resonance imaging (MRI) is also offered as a surveillance modality to some women, although availability varies across New Zealand, with women in some areas offered publicly funded MRI surveillance. Women are encouraged to be “breast aware” and to report any changes such as nipple discharge, pain, swelling or lumps to their doctors promptly. Mammography is difficult in younger women because their breast tissue is often dense, making the mammograms difficult to interpret. As a result of this difficulty, a number of studies have investigated the effectiveness of other surveillance modalities including MRI for young women (Kriege et al, 2004; Kuhl et al, 2000; Kuhl et al, 2005; Warner et al, 2001; Warner et al, 2004). These studies have concluded that breast MRI is significantly more accurate than clinical breast examination, high-resolution ultra-sound and mammography (Kriege et al, 2004; Kuhl et al, 2000; Kuhl et al, 2005; Warner et al, 2004). These findings prompted the American Cancer Society to include screening by MRI in its guidelines for women with approximately a 25-50% or greater lifetime risk of breast cancer (Saslow et al, 2007). The National Institute for Health and Clinical Excellence (NICE), in Britain, also recommends MRI be available annually to women with a high risk family history or a BRCA mutation between the ages of thirty and fifty years (2006). More recently Daly et al (2010) have indicated that MRI and mammography could be staggered so that these women have a form of imaging every six months, although they note that this is still under investigation.

Intensive surveillance such as this involves hospital appointments every six months and additional appointments for mammography and MRI. This degree of frequency may be
burdensome for some women, involving time away from work and travel costs. Increased anxiety, distress and worry at the time of receiving appointment letters and attending appointments for surveillance has been reported (Appleton et al, 2000; Kenen et al, 2003). In addition, surveillance is aimed at the early detection of breast cancer, at a stage when treatment is more likely to be effective, rather than at reducing the possibility of a cancer diagnosis. For those women who find living with the increased risk of breast cancer particularly burdensome, as well as for those women who wish to avoid a diagnosis of breast cancer, the option of risk reducing bilateral mastectomy may be considered.

3.7.4 Risk reducing mastectomy

Risk reducing mastectomy has been shown to be associated with a decreased risk of breast cancer both in women who carry BRCA mutations and in those assessed as high risk on the basis of their family history (Domchek et al, 2010; Evans et al, 2009; Hartman et al, 2001; Meijers-Heijboer et al, 2001). These studies all show a significantly reduced risk of developing breast cancer after surgery. In comparison, the studies by both Meijers-Heijboer et al (2001) and Domchek et al (2010) report women who opted for surveillance and went on to develop breast cancer during the follow up periods of these studies.

Risk reducing bilateral mastectomy with reconstruction is currently available in the public health system in New Zealand. Several surgical procedures are involved for women who want to have a complete reconstruction including the nipple and tattooing of the areola. Surgery for women with a diagnosis of breast cancer takes precedence over risk reducing surgery, meaning that some women experience cancellations and delays in being able to access the surgery.
3.7.5 International differences in the acceptability of risk reducing surgery

The acceptability and uptake of risk reducing surgery varies between different countries (Julian-Reynier et al, 2001; Metcalfe et al, 2008). Julian-Reynier et al (2001) conducted a survey of women attending a genetic service for the first time in the United Kingdom, France and Canada and found varying levels of acceptability of salpingo-oophorectomy and mastectomy as methods of risk reduction. British women were more in favour of salpingo-oophorectomy and British and Canadian women were more accepting of risk reducing mastectomy. In a larger study examining the uptake of surgical options in BRCA1 and BRCA2 mutation carriers over nine countries, Metcalfe et al (2008) found wide variation. Overall, 18% of the women had had bilateral mastectomy, with the highest rates of mastectomy found in the USA. The number of women undergoing risk reducing salpingo-oophorectomy was significantly higher, with 57.2% having had this surgery. Again, the rates varied between countries, however in all countries except for Poland, at least 50% of women had proceeded with salpingo-oophorectomy.

This discussion has considered the various medical options for managing the chance of developing breast and ovarian cancer in this group of women. Each option has its own risks and benefits and its own degree of acceptability to individual women, their partners and families. While the evidence for the risk reduction conferred by both risk reducing salpingo-oophorectomy and bilateral mastectomy is substantial, both procedures have significant side effects. As Esserman and Kaklamani (2010) state, genetic counsellors can be very effective in helping to educate women and their families about the risks and benefits and in providing appropriate referrals to medical professionals for more detailed discussion of specific procedures.

3.8 Lynch syndrome causing a predisposition to ovarian cancer

Lynch syndrome, also called hereditary non-polyposis colorectal cancer (HNPCC), is an autosomal dominant cancer susceptibility syndrome predisposing individuals to colorectal cancer and a variety of other cancers, including endometrial and ovarian
cancer. This study includes several participants who have Lynch syndrome, hence the inclusion of the following discussion.

Genetic Services and the New Zealand Familial Gastro-Intestinal Cancer Registry collaborate to provide risk assessments and surveillance recommendations for individuals and families with a history of colorectal and other Lynch syndrome-associated cancers. In families where the preliminary assessment and screening of tumour material indicates that genetic testing is warranted, the testing is arranged through and funded by Genetic Services.

The risk assessment process for these families is similar to the assessment of families with a history of breast and ovarian cancer. A detailed family history is collected and the specific cancer diagnoses in the family are verified using medical records and pathology information from the New Zealand Cancer Registry. The International Collaborative Group on Lynch syndrome initially established a set of selection criteria for families with Lynch syndrome in 1990, in order to provide a basis for uniformity in collaborative studies (Vasen et al 1999). These criteria, based on an autosomal dominant family history, multiple diagnoses in the family and early age of onset, were later revised to include extra-colonic cancers, particularly endometrial cancer (Dunlop, 2002). Limiting a diagnosis of Lynch syndrome to patients with a typical family history means that gene carriers may be missed if they do not have a family history of colorectal cancer (Lamberti et al, 1999). A second set of criteria, the Bethesda criteria, were developed with the aim of identifying people with tumours that should be tested for microsatellite instability (MSI – discussed below) to aid in the identification of individuals and families with Lynch syndrome (Rodriguez-Bigas et al, 1997). These are used in clinical practice to help identify individuals and families in whom testing should be considered.

In New Zealand, individuals and families who are suspected of having Lynch syndrome are offered initial screening using a technique called immunohistochemistry testing. This involves screening tumour material to look for the expression of four proteins (MLH1, MSH2, MSH6 and PMS2). Immunohistochemistry is a rapid and inexpensive screening technique that can be used to help determine whether a family should be offered mutation analysis for Lynch syndrome. It is also useful in decision making regarding which gene to analyse. The majority of tumours that have functional loss of
these genes have loss of expression of the respective protein in the tumour material (Muller et al, 2001; Vasen, 2000). If a tumour is found to have loss of expression of one or more proteins, the individual is offered mutation analysis for that gene using DNA from a blood sample.

A second tier test has recently been introduced for colorectal tumours that have absent MLH1 expression. Loss of expression of MLH1 is often sporadic so a test was needed to clarify which individuals with tumours with MLH1 loss of expression should be offered mutation analysis. The second tier test involves looking for a specific mutation (V600E) in a gene called BRAF in tumour tissue. The use of this test simplifies the assessment process and improves cost effectiveness as only families with results indicative of germline MLH1 mutations are offered mutation analysis (Jensen et al, 2010; Lynch et al, 2009).

A group of genes called the mismatch repair genes are associated with Lynch syndrome. The majority of families with Lynch syndrome in whom a mutation is able to be identified are found to carry a mutation in either the hMLH1 or the hMSH2 gene (Schneider, 2002). These are mismatch repair genes, whose role is to repair DNA segments where there has been incorrect base pairing (Nussbaum, McInnes & Willard, 2001). The mismatch repair genes PMS2 and MSH6 are also associated with Lynch syndrome, and smaller numbers of families have mutations in one of these genes.

As with BRCA mutation analysis, there are three possible results from the genetic testing – the identification of a pathogenic mutation, an unclassified variant or no mutation may be identified. In families where a pathogenic mutation is identified, individuals can clarify their own risks of developing cancer by having predictive testing for the mutation. For families where an unclassified variant or no mutation is identified, high risk surveillance recommendations are made for the whole family.

Prior to the development of immunohistochemistry testing families were offered another screening test using tumour material. This test examines the tumour for the presence or absence of microsatellite instability. An understanding of the way in which mismatch repair gene mutations result in an increased chance of developing cancer is useful in order to understand the use of this screening test. The cancers in individuals with Lynch syndrome appear to develop after the loss of both copies of the mismatch repair gene in a cell. The loss of both functioning copies of a mismatch repair gene appears to increase
the mutation rate and genetic instability within the cell (Lamberti et al 1999). The resulting genetic instability can be demonstrated by examining short repeat sequences known as microsatellites. When the pathology procedures are well controlled, approximately 85-95% of all Lynch syndrome tumours demonstrate microsatellite instability (Lynch & Chapelle, 1999).

Lamberti et al (1999) showed that the microsatellite instability phenotype in colorectal tumours is a useful tool for selecting patients at increased risk for Lynch syndrome, both in those who meet the clinical criteria for Lynch syndrome and in younger patients with apparently sporadic colorectal cancer. Microsatellite instability testing is simple and inexpensive in comparison with gene analysis and therefore it can be used as a screening test for individuals and families where a diagnosis of Lynch syndrome is being considered. Microsatellite instability testing is of particular value in families where there are perhaps only one or two affected individuals who may have had cancer at a young age (Lamberti et al 1999). These families may not qualify for genetic analysis on the basis of family history, but if their tumour is found to be MSI-positive genetic analysis is indicated.

Microsatellite testing is currently done in Australia, whereas immunohistochemistry testing is available through a number of publicly funded hospital laboratories in New Zealand. Immunohistochemistry testing is therefore the test of choice in selecting families to offer mutation analysis, with microsatellite instability testing only occasionally used when the clinical index of suspicion is high and the immunohistochemistry results are normal.

### 3.8.1 Cancer risks associated with Lynch syndrome

Approximately 5-8% of all colorectal cancers are attributable to Lynch syndrome (Lynch & Chapelle, 1999). Lynch syndrome is characterised by the development of early onset colorectal cancer, with the median age at diagnosis forty-five years (Rodriguez-Bigas et al, 1997). As with mutations in the BRCA genes, the estimates of the lifetime risk of developing colorectal and other Lynch syndrome associated cancers continue to change with new research. Early studies suggested that in families who met the Amsterdam criteria there was an overall risk of approximately 80% for colorectal
cancer and 13-20% for gastric cancer (Dunlop, 2002). Gender appears to be an important determinant of cancer occurrence in Lynch syndrome, with a greater risk for colorectal cancer for men than for women (Lynch & Chapelle, 1999; Stoffel et al, 2009).

Lynch and Chapelle (1999) reviewed a large study of Lynch syndrome mutation carriers which showed a cumulative cancer incidence by age 70 years of 82% for colorectal cancer, 60% for endometrial cancer, 13% for gastric cancer and 12% for ovarian cancer. There is an increased chance of developing several other types of cancer including cancer of the small intestine, hepatobiliary tract, pancreas, brain, urethra and renal pelvis (Lynch & Chapelle, 1999; Rodriguez-Bigas et al, 1997; Schneider, 2002; Vasen, 2000). These tumours had cumulative risk incidences below 4% (Lynch & Chapelle, 1999).

Subsequent studies have attempted to better define the risks of colorectal and endometrial cancer in individuals with Lynch syndrome. One recent study found that men had a 66% chance of developing colorectal cancer and women had a 42% chance (Stoffel et al, 2009). The risk of endometrial cancer was approximately 39% (Stoffel et al, 2009). The study concluded that the lifetime risk of developing cancer is high (approximately 70%) and that surveillance is therefore important.

A recent study pooled data from four European and North American Lynch syndrome registries to help better define the risks of cancers other than colorectal and endometrial cancer in people who carry an MLH1 or MSH2 mutation (Watson et al, 2008). It reported a lifetime risk (to age seventy years) of 8.4% for urologic tract cancer, with the risk being greater for males and individuals who carry an MSH2 mutation. The lifetime risk for ovarian cancer was 6.7%, and again, the risk was greater for those with an MSH2 mutation (Watson et al, 2008). They suggest that urologic tract and ovarian cancers occur frequently enough to warrant surveillance or, in the case of ovarian cancer, risk reducing surgery. Watson et al (2008) report a lifetime risk of 5.8% for gastric cancer and 5.4% for breast cancer.
3.8.2 Management of individuals with Lynch syndrome

The most significant risk for individuals with Lynch syndrome is the risk of colorectal cancer. Regular colorectal surveillance by colonoscopy every one-two years beginning at age twenty-two-five years has been shown to reduce the incidence and mortality from colorectal cancer in these families (De Jong et al, 2006).

Women with Lynch syndrome have a significantly increased risk of developing endometrial cancer. Endometrial cancer has an easily detectable premalignant stage, supporting the option of surveillance using a combination of trans-vaginal ultrasound and endometrial biopsy starting at age thirty-five to forty years (Koornstra et al, 2009).

As discussed above, surveillance for ovarian cancer is not effective in women with BRCA gene mutations and the currently available evidence does not support surveillance in women with Lynch syndrome. Women with Lynch syndrome should therefore be offered risk reducing hysterectomy and salpingo-oophorectomy when child-bearing is complete (Koornstra et al, 2009).

Surveillance for cancers associated with Lynch syndrome may include upper gastrointestinal endoscopy for gastric cancer and annual screening for urologic tract cancers by a combination of one or more of the following: urine microscopy for haematuria; urinalysis with cytology; and abdominal ultrasound (Koornstra et al, 2009). Surveillance for the other cancers associated with Lynch syndrome is not currently recommended (Koornstra et al, 2009).

3.9 Conclusion

This chapter has examined the context of health provision in New Zealand in order to contextualise the provision of Genetic Services for families with an inherited predisposition to certain types of cancer. The risks of developing cancer and the options for the medical management of these risks were discussed in order to provide a background for understanding the experiences of the participants in this study. In the following chapter the methodological basis of the work is discussed, including both the theoretical position and the practical aspects of data collection and analysis.
Chapter Four

Methodological considerations: theory and practice

This study arose out of several key clinical interactions that left me wanting to better understand the experiences of women with an increased cancer risk. Decisions regarding the methodological and theoretical underpinnings of the project were therefore important in developing a piece of work in which the voices of the participants could be heard. The position of the researcher as a practitioner-researcher and the influence of this on the process of data collection and interpretation receive particular consideration. In this chapter I discuss the reasons for choosing a qualitative methodology and a feminist epistemology and ontology. The project is informed by international studies examining the experience of living with increased cancer risk and is, to the best of my knowledge, the first project to explore this experience in New Zealand. The overall methodological approach that was taken is discussed, along with a review of the literature that informed the development of the project, the development of the interview guide and the process of data analysis. Writing formed a central aspect of the inquiry, in order to develop a collective story reflecting the individual stories the women told.

4.1 Choosing a qualitative methodology

Qualitative approaches to data collection and analysis are useful when the researcher wants to uncover and understand more about a situation about which little is known (Strauss & Corbin, 1990). Researchers undertaking qualitative research believe that the reality we perceive is constructed by the contexts within which we live. In this context, there are no absolute, shared truths. Instead, “individuals create, negotiate, and interpret meanings for their actions and for the social situations in which they exist” (Kuper et al, 2008, p. 405). The ways in which we interpret our world differ depending on our social contexts. Qualitative methodology allows the voices and experiences of the participants to be heard and understood in ways that statistical representation does not allow.
There is increasing recognition of the value of qualitative research among health practitioners, and the contributions to our understanding that these studies make (Kuper et al, 2008). Bernhardt (2008) uses a number of qualitative studies with families with genetic conditions to support the idea that practitioners working in clinical genetics can learn about the impact of genetic disease by listening to the collective voices of people with these conditions and analyzing these using qualitative research techniques. In much the same way, genetic practitioners can learn about how it is for an individual client to have a genetic disorder by listening to their story during a clinic appointment. The experience of living with an increased risk of cancer has not been examined in New Zealanders before, so a qualitative, exploratory approach using in-depth semi-structured interviews was appropriate.

4.2 Feminist epistemology

This project was conceived out of the recognition that understanding women’s experiences is necessary for appropriate service and resource development. New Zealand women live their lives within a specific society, influenced by the time and period, political discourses and ideas about national identity. Central to this are ideas about being female in New Zealand. Feminist research principles have been utilised throughout the project, in particular a concern with representing the voices of the participants in the analysis and presentation of the work, and with facilitating improvements in services and information provision which will contribute to the experiences of other at-risk women in the future.

Intersectionality, or consideration of the relationships between and among different dimensions of social relations (McCall, 2005) is a central component of feminist praxis and has arisen as a methodological and theoretical consideration in recent years (Lewis, 2009). According to Brah and Phoenix (2004), “one critical thematic of feminism that is perennially relevant is the important question of what it means to be a woman under different historical circumstances” (p. 76). This is particularly relevant in a study that examines the experience of response to risk, as risk is a construction of late modernity. Intersectionality, then, considers the complex and varied effects of multiple axes of differentiation, including race (or ethnicity), gender, sexuality and social class and their intersection “in historically specific contexts” (Brah & Phoenix, 2004, p. 76). While this
study explores the experiences of a fairly homogenous group of Pakeha New Zealand women, the period in which they are living, with its specific cultural and political exposures, cannot be ignored in analysing their stories.

Feminist researchers have long challenged traditional research paradigms in which the voices of the people who live outside the dominant structures and discourses of society are ignored or misrepresented. By taking a feminist epistemological approach, the focus of the project turns to the sharing of the women’s experiences and allows their voices to be heard. Feminist approaches arose out of political practices aimed at facilitating change in women’s lives by first producing knowledge about their social circumstances (Alice, 1999). Feminism has provided a critique of much which was previously taken for granted, particularly assumptions regarding male centrality (Beasley, 2005). Principles of feminist research include placing a desire to generate knowledge about women’s lives and their lived experiences that will influence service planning and delivery at the centre of the research process (Coy, 2006).

Feminist research epistemology does not seek to generalise women’s experiences in the pursuit of an ultimate truth. Instead, it seeks to provide multiple, subjective understandings of ways of being a woman. In keeping with a postmodern approach to research, findings of a project like this one are recognised as a narrative that provides a time and context bound illumination of the “truth”, “a truth limited by the constructions and interpretations of both the researcher and researched...” (Grbich, 2004, p. 28). This project does not seek to make broad generalisations about the experience of living with and managing an increased cancer risk. Instead, it seeks to explore and describe the experiences of a group of thirty-two Pakeha New Zealand women, to begin to develop an understanding of what it is like for women living in New Zealand to have this risk. The study also seeks to add to the growing body of international literature about the experiences of living with risk. The truths contained here are those of the women who shared them, they are the truths of their lived experiences. The knowledge gained from this study will be used to create resources for women living with an increased cancer risk and to inform service planning as we continue to develop the concepts of multi-disciplinary services for surveillance and risk reduction.
4.3 A consideration of the importance of ontology

Choosing a feminist ontology, a woman’s way of being, allows for the development and extension of knowledge through a collective and shared experience, which recognises the impact of the position of the researcher on the development of knowledge. The stories and experiences in this thesis are the collective experiences of the women interviewed for the study, interpreted through the lens of a practitioner-researcher working with these women and many others like them, on an almost daily basis. The stories these women tell become collective as they are brought together for the analysis and as they are woven with the many experiences of the women who have shared their stories with me in my professional capacity as a genetic counsellor. The stories of the women I have met professionally become part of the greater story because of the approach I have taken to this research.

Laurel Richardson (1990) describes collective stories as narratives that give “voice to those who are silenced or marginalised” (p. 25). Collective stories involve the creation of narratives about a category or group of people, for example, women who carry a BRCA mutation, so that individuals who carry a BRCA mutation can read the stories and respond with recognition (Richardson, 1990). As Richardson (1990) suggests, by binding people together through the telling of their collective story, we may help to reduce the isolation that comes from feeling as though you are the only person having this experience.

Whilst realising very early on that the role of genetic counsellor might overlap with that of researcher, I initially thought, naively, that I could somehow maintain a clear boundary between the two roles. It very quickly became obvious that the boundary was blurred and that a more appropriate approach would be to acknowledge the added richness that my professional experiences and understandings could bring to the research. The importance of reflexivity is now well-recognised in qualitative research, particularly that which privileges a feminist epistemology (Coy, 2006; Holland & Ramazanoglu, 1994; Jarviluoma et al, 2003; Mauthner & Doucet, 1998), so this became the first “tool” in the process of acknowledging and drawing on the benefits of the dual roles afforded by being a practitioner-researcher. I then turned to the literature, to examine the ways in which other researchers have managed the blurred boundaries afforded by practitioner research. The concept of a continua from outsider through to
insider resonated with my position, so that I have come to consider myself as an “outsider-alongside” the women whose stories and experiences I am seeking to understand.

An understanding of my ontology, my way of being, and the place where I stand in this research, is important in order to understand the lens through which the data has been considered, analysed and interpreted. I am a seventh generation Pakeha New Zealand woman, a woman with a post-graduate education, and the mother of two daughters who have grown from middle childhood to their teenage years during the course of the project. I am a similar age to a number of the women who participated in the project, in particular, I am the age at which many of these women are having risk reducing salpingo-oophorectomy and beginning an early menopause. I have been a practicing genetic counsellor in New Zealand for nearly ten years, during which time I have met with many women who are living with an increased risk of breast and ovarian cancer. Along with a breast surgeon, I have been instrumental in developing a multi-disciplinary clinic attended by women at high risk of developing breast cancer. Regular attendance at this clinic has deepened my understanding of women’s experiences of attendance at a surgical outpatient’s clinic and of the often very time-limited discussions that can occur in this setting. During the period when the data was being analysed, I helped to facilitate a workshop for women who carry a BRCA gene mutation and their families. Over forty people attended this workshop, and the discussions that occurred during the course of that day became part of the experience that I brought to the project.

In addition to my professional location within a clinical Genetic Service in New Zealand, I was a client of this service during the period when I was having my children, prior to training as a genetic counsellor. My experience as a client informed my decision to re-train. While my attendance at an appointment in the Genetic Service was not associated with a familial cancer risk, this experience provided me with insight into being “on the other side”. At the same time, I had my own experience of living with a potentially hereditary reproductive risk. The combined experiences of being a Pakeha New Zealand woman, a past client of the Genetic Service and a practicing genetic counsellor cannot help but influence the collection and interpretation of the stories and experiences that make up this project. It is impossible to impartially set aside the interactions with clients with whom I am currently working. Instead, I have chosen to write about these interactions and explore the ways they add to my understanding of the
data in my research journal, practicing the reflexivity that is so important to this type of qualitative enquiry. Continuing to work as a genetic counsellor during the course of the research has led me to question and examine my own practice and that of my colleagues in light of the observations made by the women interviewed for this project. These questions and experiences inform the process of understanding the data and form part of the research inquiry.

4.4 Negotiating dual roles: Combining research and clinical practice

My interest in conducting this research was initially sparked by my professional role as a practicing genetic counsellor working in a Genetic Service in New Zealand. While I work in a general genetic clinic, a significant proportion of my workload is made up of people with a family history of breast and ovarian cancer. As the research has continued, as new ideas, themes and theories have unfolded, I have had a parallel role in clinical practice, seeing women who are facing the same decisions as the women in the study group. I therefore encounter the issues the women raise both as a practicing genetic counsellor and as a social science researcher who chose to research a topic that I encounter daily in my working life. Increasing numbers of genetic counsellors are pursuing research and doctoral studies (Wallace et al, 2008), some of whom are combining research with their clinical roles. As the numbers of people undertaking practitioner research increase, our understanding of the potential challenges and ethical dilemmas that may arise will no doubt develop. The challenges and ethical dilemmas associated with combining the roles of practitioner and researcher are being considered in a number of fields where researchers have overlapping roles (Bell & Nutt, 2002; Coy, 2006). The experiences of these practitioner-researchers are helpful in understanding my own experience and in informing future research undertaken by practicing genetic counsellors.

Ethical challenges when doing interview-based research at the same time as working as a genetic counsellor have previously been identified by genetic counsellors. Mary-Anne Young et al (2005) describe ethical dilemmas they encountered when interviewing people who the interviewer recognised to be relatives of people she had seen in the genetic clinic where she worked. They describe the problems associated with resisting
the urge to step outside of the role of an interviewer and researcher and into a clinical role as a genetic counsellor. An independent interviewer was contracted to conduct the interviews for this study, however all other contact has been through the Genetic Service and the central involvement of a practicing genetic counsellor was made explicit in the initial invitation to participate in the project. While this decision meant avoiding the difficulties Young et al (2005) described during the interviews, other challenges associated with the dual roles arose during the course of the project.

Practitioners entering into a research project that overlaps with their clinical responsibilities face “multiple responsibilities” that external researchers may not face (Bell & Nutt, 2002). Approximately half the women who chose to be interviewed for this study had previously been seen by me when they attended for genetic counselling. While they were no longer active clients of the Genetic Service, rapid developments in the field of cancer genetics mean that families sometimes re-contact the service in the years following their initial assessment. As previously noted, I have been involved in establishing a multi-disciplinary clinic, which a number of these women attend. The potential for role conflict and for a blurring of the boundaries between the role of genetic counsellor and that of researcher was anticipated during the developmental stages of the project. Regular discussion and reflection of events that challenge the boundaries of each role have occurred both with my research supervisor and with my clinical practice supervisor.

Perhaps the most significant boundary challenges that have occurred have been in relation to researcher response to events described by a few of the participants. As noted below, a few participants comment on aspects of their genetic assessment that are incomplete or for which they would like further explanation. Several times the interviewer encourages these women to re-contact the Genetic Service to follow up on their concerns. As a practitioner, I am aware that these women have not re-established contact and have debated the possibility of the Genetic Service initiating the contact. Some of these comments have evoked a sense of personal and professional frustration. Catherine Kirkwood (1993) examined the place of personal response to her own research with women leaving abusive relationships and concluded that her personal responses, including her emotional responses, formed an integral part of the data analysis and informed her understanding of using a feminist approach. Paying attention to these subjective feelings has been critical during the data interpretation phase, to
ensure that these women’s experiences are represented honestly. Recognising my own feelings of frustration and exploring the possible sources of these has played an important role in my coming to an understanding of these women’s experiences.

The boundaries that exist in the relationship between practitioner-researchers and participants are, at times, fragile (Bell & Nutt, 2002). The decision to contract an interviewer was made in the hope that this would help maintain ethical boundaries between the respondents and the researcher. Acknowledging that the desire to re-contact participants occurred highlights the way in which the potential for crossing the boundary between researcher and practitioner exists even when the researcher does not do the interviews. As Reay (1996) acknowledges, there is sometimes a temptation to leave out of the analysis accounts that are uncomfortable for the researcher. Consideration of my own discomfort and frustration has been important during the process of analysing these aspects of the data and has resulted in an increased appreciation of the difficulties some women face in accessing medical services.

Another area in which the potential for boundary crossing occurred is when a client has made comments during a clinic appointment that I wanted to ask more about because it would help to inform my research. The discipline of maintaining a research journal throughout the period of undertaking this project has been helpful in providing a place to record and reflect upon these interactions. I have had clinical experiences of clients asking questions such as “Will having my ovaries removed make me more like a man?” As a clinician my role is to explore this question with the client to ensure she has accurate information and understanding so that she can make an informed decision regarding surgery. As a researcher interested in the impact of increased cancer risk on a woman’s sexuality, I am fascinated when I hear comments such as this, because of the questions it raises about what women understand about the function of their ovaries. The challenge here lies in working out what place these comments have in the research, and whether they have any place at all. A question such as this raises questions about how much some women understand about ovarian function and offer us an insight into how well we, as clinicians, are doing at providing information that our clients can understand and remember. Interactions such as this also remind me that each of the women attending a clinic has a different starting point in terms of their own knowledge about how their body works, and of the importance of individualising the information given to each person. Interactions of this nature inform the research process because of
the ideas, questions and discussion they stimulate for the researcher. As other practitioner-researchers have done before me (Bell & Nutt, 2002; Coy, 2006), I have come to the conclusion that as a genetic counsellor conducting research I must acknowledge that I have both roles and accept the fact that each role will, at times, inform and enrich the other.

4.4.1 Researcher reflexivity

The challenges associated with researching a group that the researcher has a work-related or personal association with are receiving considerable attention in sociological literature (Bell & Nutt, 2002; Coy, 2006; Humphrey, 2007; Kirkwood, 1993; Moore, 2007; Tang, 2006). In a paper entitled 'This Morning I'm A Researcher, This Afternoon I'm An Outreach Worker’, Maddy Coy (2006) described the dilemmas she faced while undertaking research with young women working in the sex industry at the same time as working as an outreach worker for an organisation that provided services for these women. The title of Coy’s paper accurately describes the challenges of identity I faced when working on this project in the area in which I also undertake clinical work. Coy (2006) described the ongoing process of reflection and negotiation that occurred during the research, including descriptions of events that she recorded in her research journal when the overlap between her roles seemed too great. In the same way, my research journal contains descriptions of instances when an overlap in roles occurred, for example a description of a telephone conversation with a research participant who phoned with a clinical query the day after I had undertaken the initial detailed reading and analysis of her interview transcript. Caroline Humphrey (2007) conducted research into self-organised groups in trade unions in Britain at the same time as being a member of a self-organised group. She considered the personal, professional and political dilemmas that arose during the course of the project. Both Coy (2006) and Humphrey (2007) identify the importance of reflexivity in managing the challenges posed by undertaking research in an area in which one has a dual role. They utilised discussions with colleagues and supervisors and the practice of keeping a research journal as means of facilitating the practice of reflexivity, methods which I have also employed.
At the heart of feminist research writing is the concept of reflexivity, the understanding that our autobiography as the researcher is a crucial part of the research. An awareness of the role that the researcher’s biography played was initially recognised in relation to its impact on the data collection and extended to consider the impact during the data interpretation and theorising stages of the research process. Self-reflexivity requires the researcher to be aware of the self in the project, including acknowledging the socially constructed nature of their own beliefs, and the impact the self has on the research process (Grbich, 2004). Researchers are encouraged to locate themselves within the project and the analysis, in order to make explicit the impact of their biography and beliefs on the research process. The word reflexivity comes from “the Latin reflectere which means “to bend back upon itself” (Humphrey, 2007, p. 13). The reflexive researcher considers the ways in which the research findings are filtered through their own interpretive lens and acknowledges the ways in which their own history, experiences and theoretical perspectives are reflected in the interpretation (Allen, 2004). Feminist academic writing has made a significant contribution to our acceptance of the legitimacy of reflexivity in social research (Ellis & Bochner, 2000). Grbich (2004) notes that reflexivity may be seen as a “self-conscious conversation” (p. 72) recorded in a research journal and sometimes made public in the form of articles exploring and documenting this process.

4.4.2 Insider Outsider Status

The concept of insider outsider status is used by social science researchers to help understand and manage the complexities associated with being a practitioner-researcher. This concept is perhaps useful when considering how the dual roles of genetic counsellor and social science researcher fit together.

Robert Merton (1972) gave an early definition of insider research, defining “the insider as an individual who possesses a priori intimate knowledge of the community and its members. The word “community” is a much wider concept than just an organization, and possessing intimate knowledge of it doesn’t necessarily mean being a member of it yourself. So being an insider researcher is
Outsider research is research where the researcher is not \textit{a priori} familiar with the setting and people they are researching (Hellawell, 2006).

Using definitions like these, one can immediately see how a genetic counsellor may have “insider” information about the group that they are researching. Genetic counsellors bring extensive professional knowledge and experience to a research project of this nature, including detailed information about how a cancer risk assessment works. Genetic counsellors are familiar with the literature around decision making and response to positive and negative test results and have seen many women make the journey from referral through to receiving test results. In addition to professional experience, practitioner-researchers may have other things in common with the participants, for example, shared gender or ethnicity, similarity in age and similarity in the ages of children. There are likely to be a number of variables that the researcher has in common with the participants, regardless of the study design. The independent interviewer involved with this project is not a genetic counsellor, but she too shared some level of insider status because she has been involved in other projects about inherited conditions (Gray, 1995), and she is a Pakeha New Zealand woman of a similar age to a number of the participants. However, while both the interviewer and the researcher bring some prior information to the project, we are not insiders in that neither of us has an increased risk of ovarian cancer and we have not been faced with the decisions that the women in the study group are faced with.

Professional experience, such as that brought to a project by a practitioner who is familiar with the field, provides the researcher with a rich knowledge base and source of insight, which may increase the theoretical sensitivity of the project. As the reports by writers such as Coy (2006), Kirkwood (1993) and Humphrey (2007) demonstrate, the process of analysing data in a field with which the researcher is deeply familiar provides an additional source of theoretical sensitivity because insight and understanding grow as one studies and becomes familiar with the data (Strauss & Corbin, 1990).

The perspectives of insiders and outsiders have advantages and disadvantages in research both from practical and intellectual perspectives. The advantages and disadvantages are present during the data collection phase as well as during the analysis.
For example, previous interview-based projects in New Zealand have suggested that Pakeha New Zealanders are likely to be more open about personal topics if the interviewer is someone they don’t know, whereas Maori and Pacific People are more comfortable talking about personal topics with an interviewer who they already know (Fleming, 1997). Many researchers now agree that the idea of insider outsider status is a series of continua and that researchers may move backwards and forwards along these continua during the course of the project. Whatever one’s status, the important thing is to acknowledge and make explicit one’s position.

Like other researchers, I have at times, felt uncomfortable with the position afforded by being both a practicing genetic counsellor and a researcher. As Tang (2006) suggests, being self-reflexive requires the researcher to consider the boundaries of each role and the ways in which shared knowledge or experiences may contribute to a deeper level of insight into the community one is researching. The issue of positionality may be resolved by use of the concept of being an “outsider within” (Tang, 2006), a position that has some relevance to my position of having detailed knowledge of the issues faced by the women I am researching but not sharing the experience of living with this risk. Perhaps a more appropriate concept would be that of an “outsider alongside” the women whose experiences I am seeking to better understand. When the complexities that arise from being a practitioner-researcher become particularly challenging, it is comforting to remember Humphrey’s observation that “the perpetual crossing over between life-worlds gave birth to a complex narrative which surpassed anything that I could have produced had I been simply an insider or an outsider.” (Humphrey, 2007, p. 15).

4.5 Developing the project

The early development of this study was influenced by studies done overseas, particularly work done in the United Kingdom by Nina Hallowell and colleagues (1998, 2002, 2004). Hallowell’s body of research in this area began with a study involving observations of genetic counselling appointments for familial breast and ovarian cancer and face to face interviews with the women who attended these appointments. She went on to interview women about their experiences of premenopausal prophylactic salpingo-oophorectomy and surveillance for ovarian cancer, and has also explored women’s
experiences of considering or undergoing prophylactic bilateral mastectomy. These studies include a detailed consideration of the effect of surgical means of risk reduction on a woman’s sense of identity as a woman and on her image of her body. While the majority of women in Hallowell’s studies were positive about the decisions they had made, including decisions to proceed with risk reducing surgery, they reported costs as well. The costs of surgery included negative effects on body image and gender identity. Lloyd and colleagues (2000) conducted interviews with ten women who had undergone prophylactic bilateral mastectomy and with the partners of eight of these women. As with Hallowell’s studies, most of these women did not regret their decision to undergo surgery, but did experience varying levels of difficulty adjusting to their altered body after the surgery.

Another early study which was influential in the development of this study was conducted in Australia in the late 1990’s by Bettina Meiser and colleagues. This study specifically addressed the experience of prophylactic salpingo-oophorectomy, reporting the findings of interviews with fourteen women who had had a prophylactic salpingo-oophorectomy, six of whom were premenopausal at the time of the surgery. Meiser et al (2000) reported sexual dysfunction among the small group of premenopausal women who had undergone surgery. A second, larger Australian study, explored the experience of genetic testing for a BRCA mutation among unaffected women who had had predictive testing for a familial BRCA gene mutation (Lim et al, 2004). The women interviewed for this study included the option of risk reducing surgery as an advantage that came with knowledge of carrying a BRCA mutation, although this study did not explore the experience of having the surgery.

Other studies have also found that knowledge of mutation status is constructed as an advantage by most women. D’Agincourt-Canning (2006) conducted an ethnographic study with thirty-four Canadian women from families with a BRCA mutation. She reported that genetic testing provided an opportunity for people to confront cancer-related fears and take steps to deal with this threat. Again, the experience of undergoing risk reducing surgery was not explored in this study; however a number of women indicated their intention to proceed with surgery based on the knowledge that they carried a BRCA mutation.
In an American study, Babb et al (2002) interviewed thirty women undergoing surveillance for ovarian cancer and thirty women who had had a salpingo-oophorectomy. They found that most of the women who had undergone surgery were enthusiastic about their decision. These women reported a need for their doctors, family members and friends to understand their very real and powerful fear of developing ovarian cancer. Kenen et al (2007) also found that the majority of women in their study considered the reduction in cancer-related fear and anxiety were worth the problems associated with bilateral risk reducing mastectomy.

In a study exploring the long term impact of genetic testing for BRCA mutations, Van Oostrom and colleagues (2003) combined interview and questionnaire data and noted that genetic testing for BRCA mutations does not appear to have significant mental health risks. Women who carried a BRCA mutation reported that risk reducing surgery resulted in reduced cancer-related fear but that women who had surgery reported less satisfaction with their bodies and sexual relationships. This study was conducted in The Netherlands, where demand for prophylactic mastectomy is high. The authors suggest that high demand and societal acceptance of this surgery is likely to result in a more positive view of the surgery; however they caution that the impact of surgery on body image and sexuality should not be under-estimated.

The collective findings of these studies indicate that most women cope well with the knowledge that they carry a BRCA mutation, or that they are at increased risk of breast and ovarian cancer on the basis of their family history. As Lim et al (2004) noted, there may be a period of initial emotional turmoil, but for most women this is short-lived. Risk reducing salpingo-oophorectomy is reported to be acceptable to the majority of women studied, with most women noting that the benefits in reduction of anxiety and fear outweigh the problems associated with an earlier than “expected” menopause. While risk reducing mastectomy is seen as more complex and problematic, most women who choose to undergo this surgery do not regret the decision. Given the number of women having genetic testing and considering risk reducing surgery, exploration of their experiences is still relatively limited, particularly when one considers that the majority of these studies are based on interview data collected from small numbers of women.
As previously discussed, I became increasingly aware that the experiences of New Zealand women living with an increased risk of breast and ovarian cancer had not yet been explored. My clinical experience as a genetic counsellor in New Zealand, and many discussions with colleagues, suggested that the experiences of women in New Zealand were likely to be similar to those of women overseas. New Zealand has a somewhat different social and political history from the countries in which other studies have been conducted and these factors are likely to influence the conditions under which these women are making their decisions. A study exploring the experiences of New Zealand women therefore had the potential to contribute to the growing international body of literature about the experience of living with an increased risk of breast and ovarian cancer, and in particular to the limited knowledge about the impact of risk reducing surgery on body image and sexuality.

4.5.1 Ethics and Funding

During 2005 the Todd Foundation Centenary Fund was open to research applications where the focus was on rare genetic diseases. An application for funding for interviewer costs, travel and transcription costs was successful.

Approval for the project was sought through the Multi-Region Ethics Committee and obtained during November 2006. The “invitation to participate” letter, an information sheet and consent form were developed prior to applying to the ethics committee. Minor modifications were made to these forms at the request of the ethics committee.

Participants were initially sent a letter inviting them to participate, with a copy of the study information sheet attached. Included with the letter was a form for the participant to return if they wished to participate, along with a reply paid envelope. These forms were returned to the researcher, who then passed them on to the interviewer. The letter explicitly stated the researcher’s role in the clinical genetics service. The interviewer took a second copy of the information sheet to all interviews and obtained written consent prior to starting the interview.

The issue of benefit to research participants was addressed in the information sheet, which noted that anecdotal evidence suggests that some women find it helpful to discuss their experiences with someone who is not directly involved in their care. Provision was made for women who had questions or wanted to have further discussion after
reviewing their experiences to contact the Genetic Service and speak to a genetic associate who was not involved in the research project.

4.6 Developing the interview guide

Using the findings reported in several studies lead by Nina Hallowell (1998, 2002, 2004), Meiser et al (2000), and Van Oostrom et al (2003), along with knowledge generated from clinical experience and discussions with supervisors and the independent interviewer, an interview guide was constructed (Appendix 5). Semi-structured interviews using an interview guide are useful when the research has a fairly clear focus as they can be used to address specific issues (Bryman, 2004). The initial interview guide included demographic information (date of birth, ethnicity, education, employment and number and ages of children) at the beginning, followed by an invitation to tell the interviewer about their personal and family experiences of cancer. The interviewer almost always initiated the discussion by suggesting the respondent tell her about how she became involved in the project. Most of the women appeared to need little prompting to talk about either their own cancer diagnosis or their family history. A number of respondents got out copies of their family trees and correspondence from Genetic Services to refer to during the interview. Most women spontaneously introduced the concept of genetic testing as part of their family cancer story, which was in keeping with the positioning of this topic near the start of the initial interview guide. These topics remained at the beginning of the interview guide after it was revised.

The questions and prompts about body image and sexuality were initially placed towards the end of the guide, based on an assumption that women might be more comfortable discussing a potentially “embarrassing” or uncomfortable topic when they had developed some rapport or sense of familiarity with the interviewer. Other topics included the genetic counselling experience, sources of information, trust associated with these sources, the decisions women had made in the context of an increased cancer risk, sources of support and changes over time. The initial topic guide was used for the first eight interviews. During the period when these interviews were conducted and transcribed, I was in frequent contact with the interviewer, and on the basis of these discussions and the tensions apparent in the early interviews, the interview guide was then revised (Appendix 6).
The difficulties with the initial interviews were primarily associated with the use of the word “sexuality”. This word is used in the academic literature that examines the impact of a wide range of issues, including a diagnosis of breast cancer, a terminal illness, or a premenopausal salpingo-oophorectomy on an individual’s “sexuality”. Given the frequent use of this word in the academic literature, the assumption that women would have ideas about what the term “sexuality” meant to them was made. Following on from this, was the assumption that women would be able to use their own ideas about the meaning of sexuality to explore the impact of the cancer risk on this concept. During the initial interviews it became clear that more specific questions or conversation prompts were needed. To this end, the topic guide was altered. After the discussion about their experience of cancer, the interviewer asked about the respondent’s beliefs about cancer in general. She went on to ask respondents to talk about the risk of breast and ovarian cancer and their sense of themselves as a woman. Grouped with these questions, were questions about their relationships with their families, including partners, children and extended family. The questions regarding management, knowledge, and getting information were grouped to follow this discussion. The revised topic guide proved more comfortable for both the interviewer and the respondents to work with and a number of more detailed conversations about the impact of the management choices they were faced with on their sexuality and their feelings about their bodies ensued.

Both sexuality and feelings about bodies are topics that are not widely and openly discussed in New Zealand society, particularly by older women. When discussing their family history, several women talk about the difficulties of getting accurate information about cancer diagnoses in previous generations, when illnesses such as breast and gynaecological cancers were grouped under the euphemism of “women’s troubles”. During the interviews, references are made to “womanly bits” and “down there” to refer to women’s genitals, by women of varying ages. While several women talked quite openly about changes to their bodies and their intimate relationships associated with risk reducing surgery, a number of women made relatively limited comments or simply agreed or disagreed with the interviewer’s questions or observations.

Interviews are interactional events modelled on the idea of a conversation in which there are two participants (Bell & Nutt, 2002; Holland & Ramazanoglu, 1994). Both the interviewer and the participant are involved in creating the data. While a conversation with a friend, colleague or family member may be a relatively equal undertaking in
relation to how much each person talks and listens, in a semi-structured interview the expectation is that the respondent will talk and the interviewer will listen much of the time. Even with people with whom we are familiar, it can be difficult to talk about topics that are often viewed as private, and yet this is what the respondents in this study were asked to do.

The nature of qualitative, interview-based research investigating personal and often sensitive aspects of people’s lives means that participants are actively encouraged to talk about intimate aspects of their lives (Birch & Miller, 2000). Research interviews are a distinct form of social relationship, and may be a catalyst for individuals to revisit private and difficult experiences (Birch & Miller, 2000). Holland and Ramazanoglu (1994) suggest that it “can be very difficult for respondents to talk about sensitive issues with an interviewer” (p. 138). Several recent studies have examined the issues for researchers conducting research about sensitive subjects, identifying issues and possible strategies to help manage the research (Dickson-Swift et al. 2006; Dickson-Swift et al., 2008; Stevens et al, 2010). Dickson-Swift et al (2006) and Stevens et al (2010) note that the development of rapport between the interviewer and participants is particularly important in research that involves discussion of sensitive topics, to create an environment of trust and openness. This may involve self-disclosure on the part of the interviewer (Dickson-Swift et al, 2006). Both Dickson-Swift et al (2008) and Stevens et al (2010) consider appropriate training and support for interviewers to be important when researching sensitive topics. This may include training for the interviewers in basic counselling skills and in areas such as managing distress, along with formal supervision, structured mentoring and opportunities for debriefing. Training may be specific for the research project, for example in their study regarding survivorship issues after a diagnosis of gynaecological cancer, Roberts and Clarke (2009) ensured that the interviews were carried out by an interviewer with training in sexual health. In retrospect, it may have been appropriate to utilise an interviewer with sexual health training for this study.

Representations of sexual imagery are pervasive within the media and popular culture. Young, attractive, often scantily clad women are used to encourage us to buy a huge range of products. Television shows and movies are replete with sexual imagery and behaviour. The music industry contributes lyrics filled with sexual innuendo and outright suggestion, accompanied by pounding beats and provocative videos. The images
portrayed by the media are of people who are healthy and attractive, and sexual images are associated with heterosexual, penetrative sex (Hordern & Street, 2007). “Deeply embedded in many of these images are statements about contemporary sexuality and modern day intimacy that leave their mark on health care consumers” (Hordern & Street, 2007, P. 1705). Even surrounded by this imagery, many of us find it difficult to talk about our bodies and our intimate relationships. Complicating this is the fact that terms such as sexuality and intimacy have different meanings for different people and at different stages of life (Hordern & Street, 2007).

One area in which a dialogue about discussing sexuality and body image is occurring is in the field of cancer care. As cancer treatments have improved and many people are living for years after a cancer diagnosis, the impact of the diagnosis and treatment on other aspects of people’s lives, including their sexuality, is being acknowledged. Intimate relationships and sexual activity can be life affirming and can provide both patients and their partners with comfort and solace (Shell, 2006). Oncology nurses understand the effects of treatments such as chemotherapy on a person’s sexuality and consider education regarding sexuality to be part of their role (Lavin & Hyde, 2006). However, when asked about whether they addressed sexuality with patients, these nurses revealed that they avoided doing so, in part because of structural barriers in the oncology setting, and in part because they felt uncomfortable and embarrassed about introducing the topic (Lavin & Hyde, 2006). In a study of constructions of sexuality and intimacy after a cancer diagnosis that examined the attitudes of both patients and health practitioners, Hordern and Street (2007) found that the majority of health practitioners assumed survival was more important to patients than the impact on their intimate relationships. Many of the professionals in Hordern and Streets’ (2007) study employed avoidance strategies to evade discussing sexuality and cited barriers including lack of time and privacy that made it difficult to introduce a discussion about sexuality. In contrast, the patients in Hordern and Street’s (2007) study reported a desire to have concerns and questions about their sexuality answered. There is an underlying assumption that health care practitioners will get on and have these discussions with patients, without acknowledgement of dominant structures in health care that dictate how and when to speak to patients and what remains taboo as far as topics go (Hordern & Street, 2007). These studies indicate that talking about sexuality and intimacy is
difficult even in a setting where people are undergoing treatments that directly affect their sexuality, body image and ability to be intimate.

New Zealand women who responded to the invitation to participate in this study were offered a choice about the location of their interview. Most women chose to be interviewed in their own homes, but a few interviews took place in cafes. One woman’s husband was present during the interview and children ranging from toddlers through to teenagers were present for all or part of several interviews. The presence of other people, particularly children, reflects the realities of these women’s lives; however it may have contributed to the limited discussion about sexuality and body image during some of the interviews. The presence of other people may also have made it difficult for the interviewer to know if it was appropriate to introduce this topic.

4.7 Interviewing

Feminist researchers have long acknowledged the shared, collective and subjective nature of the data collection that occurs during semi-structured interviews. Data collection using interviews is attractive to feminist researchers because “… interviewing offers researchers access to people’s ideas, thoughts and memories in their own words rather than in the words of the researcher” (Reinharz, 1992, p.19). Interviewing is central to techniques of data collection in qualitative research, with many studies utilising interviews of one kind or another. Semi-structured interviews, using prompts and topics for discussion rather than specific questions, can open the door to the collection of rich and varied data. The biography of the researcher has a significant impact on the research project, both during the data collection phase and during the analysis. In the case of this project, the biography and presentation of the interviewer was important during the interviews, and the biography of the principal researcher has had a significant impact on the project design, data analysis and reporting.

It is now thirty years since Ann Oakley (1981) first wrote about the social interaction that occurs during a research interview and the very real difficulty of maintaining the objective, detached stance that was deemed appropriate at the time. Oakley (1981) maintained that shared gender, with both the interviewer and the interviewee being women meant that it was relatively easy to develop rapport. She was interviewing
young women having their first child at a time when she was also a young woman with children, so she shared more than just gender with her respondents, a factor which may well have facilitated the process of developing rapport. Janet Finch (1984) took up the acknowledgement with her frank discussion of the extent of the disclosure that occurred during interviews simply, she believed at the time, because two women were present. Finch (1984) writes about the concern that she experienced when she realized just how much women were prepared to share with her noting that:

“Almost all the women in my two studies seemed to lack opportunities to engage collectively with other women in ways which they would find supportive, and therefore they welcomed the opportunity to try to make sense of some of the contradictions in their lives in the presence of a sympathetic listener.” (Finch, 1984, p. 75.).

The women interviewed for this study also lack opportunities for collective engagement with other “at-risk” women, although the possibilities afforded through the internet meant that a few of them had engaged with other women online.

The observations made by Oakley (1981) and Finch (1984) have been expanded, considered, critiqued and developed over time, resulting in the present understanding of the importance of the ontology and personal biography of the interviewer. While the initial discussions were regarding the gender of the interviewer and respondent, and were particularly considered by women interviewing women, multiple other factors are now understood to play a role in the collection of data during interviews. Cotterill (1992) believes it is simplistic to suggest that shared gender is enough for women to identify with one another in an interview situation and identifies structural barriers, for example, status, class, age, race, and disability as influencing the interview situation. Riessman (1987) also indicates that shared gender and personal identification may not be enough for full knowing. Her analysis of two transcripts draws attention to the difficulty of understanding a narrative when trying to impose a white, middle class model onto an interview with a woman from an ethnic minority group. The importance of a sensitive collaboration both during the interview and during the analysis is emphasised (Cotterill, 1992). While Cotterill (1992) noted a number of potential influences during the interview process, Broom and colleagues (2009) suggest that gender has been considered in relative isolation in the context of research interviews.
Other factors including age, ethnicity and social or professional status are also likely to mediate the interview dynamic. As discussed in chapter one, the women who participated in this study were relatively homogeneous in terms of both ethnicity and also with regard to education and employment status. The interviewer who was contracted for the study was of a similar demographic. As noted earlier in this chapter, I also fit this demographic. This homogeneity may make conducting the interviews and understanding the narratives of the participants easier, but at the same time it may actually mean that subtleties are missed during the analysis because assumptions are made rather than the data being rigorously interrogated.

A potential difficulty with interviewing which is of particular relevance to the analysis of the data for this study is the possibility of the interviewee giving a “public account”. Both Ribbens (1989) and Cotterill (1992) indicate that respondents are likely to give a “public” account initially, telling the interviewer what they assume the interviewer wants to hear and what they are comfortable with disclosing. Cotterill (1992) uses the term “best face” to describe the behaviour of managing the unfamiliar interview situation. It may take several interviews to develop trust to the point at which interviewees feel comfortable giving a “private” account of their lives (Ribbens, 1989; Cotterill, 1992). The interviews recorded for this study provide a brief snapshot into the lives of women at increased risk of cancer. They are single interviews, so if it holds true that more than one interview is required to establish a “private” account; this analysis may only represent the “public” face of living with an increased risk of breast and ovarian cancer. If the women felt that they had to “put on” a pragmatic, sensible and cheerful “face” for the interview, then what we might be seeing is the “public” face. This provides a possible explanation for the strong sense of “getting on with it” that pervades many of the interviews. However, Birch and Miller (2000) comment on the emergence and popularisation of what they term a therapeutic culture in Western societies with an increase in the popularity of self-help groups and counselling. This change at a societal level indicates the possibility of a blurring between public and private accounts, indicating a willingness to disclose personal information, so this approach to living with risk may indeed hold true after several interviews with the same women. The resonance of “getting on with it” as a part of the national psyche in New Zealand also indicates that this approach does indeed represent both the public and private faces of the respondents in this study.
In recent years there has been an increasing trend towards individuals speaking very publicly about their lives, as can be seen on television talk shows and in many other forms of media (Birch & Miller, 2000). Books such as Margaret Clark’s *Beating Our Breasts: Twenty New Zealand Women Tell Their Breast Cancer Stories* (2000) are an example of a forum in which women chose to write publicly about their experiences of diagnosis and treatment. New Zealand families have chosen to speak publicly about the experience of living with an inherited cancer risk, for example one large family told their story to the *New Zealand Women’s Weekly* (Nealon, 5 November 2001). Women are also posting their stories on internet sites, for example there are a number of personal accounts on the Gift of Knowledge site. These examples, coupled with an increasing societal trend towards the acceptability and indeed expectation, that individuals will “bare all” in media interview situations, is likely to have influenced individuals’ expectations of disclosure during research interviews, so that it is reasonable to expect that what is disclosed during the interviews is in fact both the private and public accounts of the individual concerned.

### 4.8 Conducting the interviews

One of the aims of this project was to gain an understanding of people’s experiences of using the Genetic Service. It was therefore considered important that the interviews were conducted independently of both Genetic Services and Gynaecological Oncology services in order to reduce the possibility of ethical tensions arising and to facilitate open discussion about the experience of using these services. Funding was obtained in order to contract an independent researcher experienced in conducting semi-structured interviews with people who have considered or undertaken predictive testing for other genetic disorders to do the interviews. It was hoped that this would allow the women involved to talk freely about the experience of genetic counselling and about attending surveillance appointments or undergoing preventive surgery.

As with all the decisions made during the design and completion of a research project, the decision to contract an interviewer has had both advantages and disadvantages. The respondents appeared to talk comfortably about their experiences with various hospital services, making comments that are both favourable and critical. The use of an independent interviewer resulted in some frustration with instances in interviews where
topics, specifically those related to body image and sexuality, were not explored to the extent that would have been useful during the analysis. It is possible that the interviewer was not particularly comfortable exploring these topics with the respondents, particularly during the earlier interviews. The more detailed discussions regarding body image and sexuality occur in the interviews conducted later in the project, after the interview guide was altered, indicating that interviewer comfort with the topic increased with time, familiarity and the altered positioning of the topic.

The interviews lasted between forty minutes and two hours and were conducted over an eight month period. As previously noted, the participants chose the location of the interview, with the majority choosing to be interviewed at home. A radio was playing in the background of one interview and the interviews that were done in cafes were difficult to hear at times.

The interviews were transcribed verbatim by a paid transcriber. In keeping with feminist practice regarding minimising the unequal power relationships inherent in the research setting, the respondents were given the opportunity to review and alter their transcript. They were sent two copies of the transcript with a letter inviting them to add any comments, thoughts or clarifications to one copy and then return it in the envelope provided. They were also asked to put a line through any comments they wished to have removed from the transcript. The letter noted that the transcript had been typed in the way that we talk, including repetitions and the use of phrases such as “you know” and “yes” at the ends of sentences. Approximately half the women made comments or changes to their transcript, including one woman who re-typed her transcript with significant editing to improve the grammar and remove the pauses and repeated words that are common as we speak.

The first eight interviews were conducted during a four week period just prior to the Christmas break. During this period, these interviews were transcribed and read for emerging themes. Difficulties associated with the initial topic guide were identified in consultation with the interviewer and the guide was altered, as previously discussed. The remaining twenty-four interviews occurred during the next seven months and were transcribed and returned to the participants for editing during this time. During the process of transcription and editing, a précis of each interview was constructed, including demographic data and an outline of the initial impressions of their experience.
Once all the interviews were returned the detailed data analysis began, using a thematic approach as described by Braun and Clarke (2006). The tapes were listened to with the transcripts to hand. The transcripts were then read, with initial ideas and potential codes and themes noted in the left hand margin. These ideas were listed, grouped and considered in order to identify emerging patterns. Mauthner and Doucet (1998) describe this initial stage as a process of “getting to know the data” and note that the process at this stage can feel intuitive. Corbin and Strauss (2008) also suggest that, at this stage, analysts have to follow their instincts in identifying what seems to be important in the data. While this may be true to some extent, a deductive approach to data analysis allows particular consideration of aspects of the data related to the specific research questions. At this stage, all the comments relating to body image or sexuality were identified, as were comments that referred to management choices, sources of information and relationships. An extensive list of codes was developed during this stage of the data analysis and these were grouped into possible themes.

The transcripts were then re-examined with specific codes and themes in mind. At this stage themes began to develop. For example, as the codes associated with women’s “attitudes” to being at increased risk were considered, the theme of “ways of approaching risk” was identified and named. Within this grouping, specific ways in which the women approach their risk were identified and named. A process of comparison of similarities and differences of the theme, as described by Corbin and Strauss (2008) was undertaken. In the process of comparing instances of the occurrence of the “ways of approaching risk” theme, the observation was made that this theme was generated by an overall impression of each interview as well as by individual incidents within the interviews. Similarities and differences between the respondents and within the emerging themes were identified and used to generate further questions for consideration. Corbin and Strauss (2008) suggest that comparative analysis forces researchers to examine their own assumptions and potential biases and results in an increased likelihood of identification of variation as well as general patterns. Consideration of the ways in which women approach risk and the observation that the majority of women approach their risk in similar ways resulted in a careful consideration of the differences between the way that the majority of these women appear to approach risk and the small group who take a different approach. Close reading of the transcripts identified similarities in specific comments that the two groups
made indicating the effect of a societal discourse associated with the ways we might approach risk. This process was repeated for each of the themes identified.

During the course of the data analysis my supervisor read six of the interview transcripts and coded them, in order to establish replicability of the codes and emerging themes. Having more than one researcher read and code the interview transcripts is recognized in grounded theory and other qualitative research methods as a way of obtaining multiple interpretations of the data (Grubs & Piantanida, 2010). The transcripts had had all identifying data removed prior to being given to my supervisor. The invitation to participate and the accompanying information sheet used language that explicitly described the team nature of the research, for example stating that “we” will transcribe the tapes and will write articles about the study. In keeping with the feminist epistemology, having a second researcher code a small number of transcripts helped to ensure that the analysis ultimately represents the multiple and subjective experiences of the participants in this study.

The data related to each theme was grouped into separate files, noting that some data appeared in more than one file. These extracts of text were coded inclusively, retaining a small amount of the surrounding text so that the context of the comment was retained (Braun & Clarke, 2006). The themes were interpreted and developed through a process of extensive reading and re-reading of the transcripts and theme files, along with reference to relevant literature and discussion with colleagues. The process of discussion and review of literature has helped to inform the decisions about which information has been chosen for interpretation and presentation, a responsibility which ultimately falls to the researcher in all projects (Opie 1992; Reay, 1996).

4.9 Researcher biography and data interpretation

It has taken some time for the subjective nature of data interpretation and the place of the researcher in the analysis of interview data to be acknowledged. Careful attention has been given to the process of “listening” to participants, rather than to the process of interpreting and representing their voices in text (Edwards & Ribbens, 1998). More recently attention has turned to the process of taking the respondents words and descriptions of their private lives, the transcripts of the interviews, and turning these
into public texts and theories (Mauthner & Doucet, 1998; Coy, 2006). Holland and Ramazanoglu (1994) highlight the difficulties associated with this process, suggesting that the interpretation of data and the formation of conclusions is a contested and unstable process that occurs in the space between the respondent’s and researcher’s lives. They suggest that there are many ways to interpret interview transcripts, which can potentially cause problems with the validity of the research. However, if we accept that the findings of a project such as this one are constructed within the context of a particular society, the use of terms such as validity and reliability give way to an understanding that realities are multiple (Grbich, 2004). In this context the findings of each project of this nature add a new layer of understanding to our collective knowledge.

As with the location and personal biography of the researcher in the interview process, the acknowledgement that the presence of the researcher has a profound effect on the data interpretation is crucial (Holland & Ramazanoglu, 1994). It is the researcher who selects the particular aspects of the data for detailed analysis and the comments that are used to illustrate themes (Holland & Ramazanoglu, 1994). Reay (1996) acknowledges the power the researcher has during the interpretation process in selecting data to use or leave out when she writes about the temptation to leave out of the analysis an account that she found particularly uncomfortable. The process of doing research with a group of participants where there is an overlap between the research relationship and the clinical relationship, as is the case with this project, adds complexity to the interpretation process.

My professional role as a practicing genetic counsellor has made a significant contribution to my understanding of the data. During the course of the project, I have recorded a number of moments during clinical interactions when events or comments have occurred that have highlighted areas of particular interest or have contributed to my understanding of these women’s experiences. These interactions become part of the collective nature of the project simply because they have occurred. By recording them, I have sought to make overt their place in the process of developing understanding.

Clinical interactions with women who had been interviewed for this study occurred on several occasions. These have informed my understanding of the research process. An example occurred when a woman who had been interviewed for the project phoned the
Genetic Service the morning after I had undertaken the initial detailed analysis of her transcript. Her voice and story were intensely familiar, so when she phoned I greeted her enthusiastically. She was clearly taken aback by this, and rightly so. She was ringing regarding a workshop we were about to run for BRCA gene mutation carriers and had no way of knowing that I had recently analysed her transcript. This interaction highlights the ways in which the stories of the individual participants can give the illusion that we know them better than we actually do. Her interview occurred at a given point in her life and contains the elements she thought appropriate to disclose at the time. This experience has heightened my awareness that the stories contained in the transcripts represent moments in time in the lives of the women who participated.

Feminist research principles privilege the position of research respondents, sharing a commitment to valuing their lived experiences. While the respondents participate in the research during the data collection phase, it is much more difficult for the respondents to participate in the process of data interpretation and analysis. Some researchers have attempted to develop processes to include respondents during the analysis; however this was not attempted during this project. The difficulties with including respondents during the analysis underscore the fact that the research relationship is an unequal one, with the researcher having considerably more power than the respondents. The selection of excerpts from transcripts to represent themes is an illustration of the unequal power relationship. Holland and Ramazanoglu (1994) suggest that researchers make explicit the principles on which they have based selection of specific excerpts. In this project several principles were used to select excerpts from transcripts. Many of the excerpts used are those that best represent or describe the theme that is under consideration at the time. For example, decision making is a major theme for these women. The following excerpt was selected for inclusion in the text because it clearly articulates the way that the decisions are cumulative, with one decision followed by others over time:

...took me most of that year to stew about it before I made the decision to contact Genetic Services, because I knew that once I made the decision to have the test done then I would potentially have bigger decisions to make and did I want to face that? [29].

Excerpts from the majority of the thirty-two women who were interviewed for this project have been included to produce a text that attempts to represent the multiplicity
of their voices. Opie (1992) cautions that researchers risk appropriating data from the respondents and leaving out significant elements during the analysis. Selecting quotes that allows the voices of multiple respondents to be present in the text helps to reduce the appropriation of data (Opie, 1992). Each excerpt is followed by the interview number so the reader can identify comments by the same respondent throughout the text, as well as identifying the multiple voices represented here. During the coding process, the data was coded inclusively, retaining surrounding text in order to maintain the context in which the comment was made (Braun & Clarke, 2006). Comparative analysis encourages the researcher to look for differences and similarities in the participant’s experiences. In some instances, excerpts that represent experiences that differ from those of the majority of participants have been used both because they encourage the exploration of why experiences differ, and because they allow those women’s voices and experiences to be present in the analysis along with those who have had similar experiences.

There is a recognised power differential between the researcher and people who participate in research projects. The principles of feminist research suggest that researchers act in ways that attempt to minimise the power differential that exists between the researcher and the participants. Researchers may do this in a number of ways during a project, for example by choosing methods of selection or invitation of potential participants that emphasise the voluntary nature of participation, interviewing in ways that seek to encourage equality in participation, and by giving participants the opportunity to read and edit their transcripts prior to the analysis.

In a project such as this, where the investigator has a clinical role and a clinician-patient relationship with some of the potential respondents, the power differential is of even greater significance. Attempts were made to be explicit about the different roles of the researcher and interviewer in the invitation letter and on the accompanying information sheet (Appendix 1). The invitation letters were sent by the gynaecological oncologist who held and maintained the database, again in an effort to make explicit the roles of each person involved in the project. The original application to the ethics committee included the letter of invitation to participate signed by the researcher. The ethics committee requested that the letters be signed by the surgeon rather than the researcher, reasoning that the database was held by the service the surgeon worked within, rather than by the service where the researcher worked. The consent form (Appendix 7) that
was discussed and signed at the start of each interview stated the voluntary nature of the participation. These were requirements of the Multi-Region Ethics Committee, from which approval to conduct the project was sought. On reflection, receiving a letter from a service provider such as a surgeon may have had the potential to taint the voluntary nature of participation in the project, as women may have felt implicit pressure to participate as a condition of future health care. Bell and Nutt (2002) examine the roles of institutional ethics committees and professional codes of ethics and conduct for professionals when the researcher is also a practitioner. They conclude that there is a possibility that these codes and practices will not cover all the situations that arise in practitioner-research and stress the importance of reflexivity in managing the boundaries of each role. The voluntary nature of participation in the study was reinforced by the inclusion of a sentence explicitly stating that participation was voluntary in the invitation letter, included at the request of the ethics committee.

4.10 Writing the analysis

During the process of writing the initial draft of this thesis, it became clear that the task associated with turning the words and stories of the participants into text, and comparing this with the existing literature, was in fact part of the analysis. As the writing progressed, the narratives and themes developed and the associations within those themes became apparent. Riessman (2008, p.4) notes that researchers “construct stories from their data”, composing narratives that draw on the dominant discourses of society to situate the experiences of the research participants. Richardson (1994) suggests that writing is in fact a method of inquiry and is therefore a part of the analysis. As the task of writing about the topic continues, we make discoveries about the topic and about our relationship to the work. Richardson (1994) states that she writes in order to learn, rather than the writing being a task at the end of the project, when the analysis is complete and the points to be made are finalised.

Writing has formed a central part of the analysis of this interview data as I have sought to honestly represent the voices of the participants and to incorporate my own positioning into the data analysis. Maria Gardiner and Hugh Kearns run workshops for Australasian Masters and Doctor of Philosophy students, emphasising the importance of writing early and often (Gardiner & Kearns, 2011). While they are encouraging writing
to complete the thesis, they also note that writing helps to direct reading, suggesting an underlying awareness that writing is an important part of the task of analysis and understanding the data.

Writing as a means of inquiry is becoming more widely recognised. Buzzanell and D'Enbeau (2009) used writing stories as a means of analysing and developing their understanding of experiences of mothering and care giving in universities. The writing stories weave together multiple forms of data that include interview data along with their own experiences and extracts from their journals and email conversations. In exploring personal journal writing, Wright and Ranby (2009) also use writing as a form of inquiry. They note that journal writing is a way of clearing information, assumptions and expectations, and in much the same way, I have found that the task of writing has created a way of organising the data, and exploring and challenging my assumptions about my initial impressions of the data.

The process of beginning to write narratives about the data and to collate the women’s stories informed the development and organisation of the substantive chapters. The material is organised in a way that is both chronological and biographical for the research participants, reflecting the sequence that many of the transcripts take. The chapters were developed through the identification of the main themes, followed by a process of grouping participant’s extracts within those themes and then developing these grouped extracts into a cohesive narrative. The material regarding risk-reducing surgery was the most difficult to organise as the issues regarding mastectomy and oophorectomy are overlapping but different.

Writing has formed one of the central methods of inquiry in this project, albeit in an unplanned and until recently unnamed way. The task of keeping a research journal is mentioned by many researchers as a central aspect of their research process and as a place to explore early ideas. I kept a journal through much of this project, and supplemented this with regular and often lengthy emails to my supervisors. These emails arose out of the physical limitations afforded by not working on the same campus as either of my supervisors, and became a place for exploring ideas prior to and after our meetings. Jarviluoma et al (2003) state that one “can only learn writing through writing” (p. 117). To this I would add that it is through the process of writing that one comes to more clearly understand one’s topic.
4.11 Conclusion

This project was conceived out of the recognition that understanding women’s experiences of living with an increased risk of developing cancer is necessary in order for clinicians to provide adequate services. Feminist research principles have been utilised throughout the project, in particular to address a concern with representing the voices of the participants in the analysis and presentation of the work, and with facilitating improvements in services and information provision which will contribute to the experiences of other at-risk women in the future. With an understanding of the underlying principles and methodological considerations to hand, we can move on to a discussion of the experiences reported by the women who participated in the project.
Chapter Five

Making big decisions: the consequences of a family history of ovarian and breast cancer

Over the years we've had so many women in the family die of cancer...
[22].

...when I was in my early 20's my Mum was 49, she was diagnosed with ovarian cancer [24].

We got a letter in August last year from a cousin... [30].

Well I was diagnosed with breast cancer... [9].

The understanding that a woman is at increased risk of developing ovarian and/or breast cancer comes in several different ways. A woman may have an extensive family history of cancer, they may have lost their mother to cancer at a young age, they may receive a family letter informing them that a BRCA mutation has been identified in the extended family, or they may themselves develop cancer at a young age. One after another, the women who participated in this study tell us their personal and family story of the cancer in their family. The majority of the stories have similarities, telling of several generations of women with breast and/or ovarian cancer, telling of the diagnosis of cancer in their mother, telling us of their own diagnosis of cancer, often against the background of a strong family history of the disease. These women speak about the losses in their family, both the loss of family members to cancer, but also of the loss of information and history when key women in the family die of cancer. As part of their “cancer story” they talk about their involvement with various medical professionals and staff from Genetic Services. They tell us about the process of the risk assessment and genetic testing, about going through predictive testing for a known family mutation, about getting their results and about deciding what to do with this information. Regardless of the means of learning of the increased risk, the knowledge that one has a high chance of developing ovarian and/or breast cancer brings with it a number of decisions. These decisions are complex and often overlapping, and may extend over a number of years.
In this chapter I explore the types of decisions women at increased risk of ovarian cancer are faced with, the sources of information they use as part of their decision making, and the factors that influence their perception of risk and the decisions they make. The issues that arise are similar for this group of New Zealand women when compared with studies conducted elsewhere, what is perhaps more specific to these Pakeha New Zealand women is the approach they bring to their decision making, which is discussed in chapter six.

### 5.1 Stories about cancer

You know it’s almost like you’re playing Russian roulette... So I’m forever balancing up, you know, when do I have the operation. And you’re balancing this up with a lot of other stuff that’s going in your life like weddings, like study, like work, like you know and, and the possibility that it might never happen... [9].

This description of the daily impact of carrying a BRCA mutation describes the complexity of balancing the information about the mutation and the risks it brings with the desire to get on with one’s life. This woman was found to carry a BRCA1 mutation after developing breast cancer in her early 30’s. She describes coming out of the genetic consultation at which she was offered BRCA mutation analysis and thinking for the first time “fuck, this thing could get me”, you know? At the time of her interview she was trying to make a decision about a risk reducing contra-lateral mastectomy and about the timing of a bilateral salpingo-oophorectomy. Much of her interview involves discussion around her options and the things that she is taking into consideration as she works her way towards the decisions.

The decisions a woman makes differ depending on their specific circumstances, as the following stories illustrate. A forty-three year old woman describes being aware of the possibility of an increased risk of ovarian cancer based on her family history for many years. She initially sought information from the family doctor and then from a new GP after she moved to a different town. While the first GP did some research and gave her the limited information that was available at the time, the second GP just laughed and said “we’re not in America” [6]. After another move, she was referred to a
gynaecologist and started having surveillance. She was seen by a genetic service and given a high risk assessment but BRCA mutation analysis was not available to her as all the affected women in the family were deceased. However

...after a while I started to feel uncomfortable that the monitoring for ovarian cancer was not very, well I couldn’t guarantee that it was going to be very successful and so eventually I decided to explore having an oophorectomy and I went ahead with that, I think I was 38 [6].

She acknowledges that this was a difficult decision to make, saying

...yes it was a hard decision to make because yeah I suppose it’s all tied up with your sexuality and walking into the unknown [6].

As she was only thirty-eight at the time of the surgery, she chose to use hormone replacement therapy (HRT) afterwards, only to have another doctor tell her that she shouldn’t take hormone replacement therapy because of the increased risk of breast cancer. She describes doing further research and making a decision to continue with hormone replacement therapy for a few years. At the time of her interview she had been using hormone replacement therapy for five years and was considering discontinuing its use. Her story illustrates the decision pathway that many of the women in the story describe; a pathway that starts with awareness that they may be at increased risk.

For some women, the knowledge of their own increased risk comes with the identification of a BRCA mutation in the family and the option of predictive testing for the familial mutation. Another woman describes getting a letter from a research consortium telling her that a BRCA mutation had been identified in the family. She describes the impact of knowing that she could now have predictive testing and says it

...took me most of that year to stew about it before I made the decision to contact Genetic Services, because I knew that once I made the decision to have the test done then I would potentially have bigger decisions to make and did I want to face that? [29].

She goes on to describe her devastation at receiving a positive result and the decisions she subsequently made regarding risk reducing salpingo-oophorectomy and bilateral
mastectomy. She also describes telling various family members and friends about carrying the mutation and about her plans for surgery and then deciding not to tell other people after receiving hurtful and unsupportive comments from a cousin and no contact from two of her closest friends.

*I got a hell of a fright because I thought that once I made the decision, everyone would be supportive. everyone, all my friends and my family were going to be there saying “we’re there for you”. It didn’t happen… the same week my [relative], who had just been tested negative, emailed me and said “I’d already decided that if I was positive this is what I would have done. I wouldn’t have had surgery, what are you doing. You need to stop, you need to think about this” and I completely lost it because I was emailing these people to say I need your support this is really, really difficult. I need your support. But instead I was getting that and then my [relative], how dare you. She was negative. How dare you. I haven’t spoken to her since.* [29].

The decision to seek information about a family history of cancer is often not made in isolation, and may involve complex negotiations within a family. One young woman talked about her mother’s death from ovarian cancer several years prior to the interview. Before her death she had a genetic counselling appointment and was offered BRCA mutation analysis. She declined testing but chose to store a DNA sample for her daughters to use in the future. The following comment illustrates the negotiation that was occurring in this family regarding whether or not to request testing of their mother’s sample:

*She has summarised our meeting, in a letter which I’ve just recently received and she enclosed a consent form should I want to pursue testing which I’m keen to do. But it’s wider than just me. And it’s really hard because I’ve got two younger sisters, one who’s pregnant and the other one who doesn’t have a partner. Because of the different stages of life that we’re at, we all feel quite differently about it and although I think we’d all eventually be very keen to know it may not be the right time at the moment* [3].
Even the decision to have predictive testing for a familial BRCA1 mutation is sometimes a collective one, as this comment illustrates:

_‘I went along merrily thinking I’ll just keep going and then all my sisters all of them banded together and decided that they were all going to be tested and they all got tested… And I thought well I can’t be left out. I can’t be the only one that doesn’t know’ [4]._

5.2 Decision making: The common thread

The common thread to all the stories is the need to make decisions. These women have identified a number of different decisions that may need to be made during the course of learning about the increased risk and making choices about how to manage the risk. The initial decision often involves a woman choosing to seek out further information about her risk. This may involve speaking to her general practitioner or another medical professional and a referral to a genetic service often results. While an individual in a family may seek the initial information to clarify her own risk, the wider family may also be involved in the decision to seek risk assessment and in decisions about initial mutation analysis in a family. If a mutation is identified in a family, individual family members then have the option of clarifying their own risk through predictive genetic testing. The women in the study raised a number of considerations when discussing their decision to have predictive testing including the timing of testing, concerns about insurance, confidentiality and ensuring they had support while going through the testing process.

While the majority of the women who underwent predictive testing in this study had a positive result, two of the women had tested negative for a known family mutation. These women indicated that there were decisions to be made after a negative predictive test including decisions about telling family members and managing their own and their family member’s feelings about their result, and decisions about reducing the amount of surveillance they were having. Most non-carriers adopt appropriate surveillance after receiving a negative genetic test result for hereditary cancer mutations, however a few people appear to need additional counselling interventions to help them adapt their risk perceptions and adopt appropriate screening behaviours (Meiser, 2005). The term
“survivor guilt” is used in the literature to describe the feelings non-carriers in families with hereditary cancer mutations may experience after learning that they do not carry the family mutation. Both the women who do not carry the familial mutation described complex emotions surrounding this knowledge, including feeling guilty that their sisters carried the mutation. Valverde (2006) uses the term “identity loss” to describe her feelings on learning that she did not carry a familial BRCA mutation, as she faced a life that no longer included waiting for the day when she would receive a cancer diagnosis. She reports that learning to accept her negative result took several years. Perhaps the women interviewed for this study who did not carry the familial mutation are still coming to accept the reality of their result.

For women with a positive test result, many decisions followed. As earlier studies have identified, women use information from genetic testing to guide their management choices regarding surveillance and risk reducing surgery (D’Agincourt-Canning, 2006; Hamilton et al, 2009; Lim et al, 2004). Along with decisions about risk management, the women in my study also described making decisions about who to tell and what to tell them and about telling the children. Two of the women discussed the way in which having a positive predictive test was impacting on their decisions about child-bearing and described seeking information about pre-implantation genetic diagnosis (PGD) and prenatal diagnosis.

As a group, these women identify many different factors which they consider when making decisions, including the way they make sense of the risk, the influence of family in decision making and their life stage. I will discuss these factors in relation to making decisions about risk management, telling or not telling family members and friends, and prenatal decisions.

5.3 Risk Perception

One of the ways in which we can begin to understand the decision making process women at high risk go through is to consider the matter of risk perception and its influence on decision making. As previously discussed, risk is conceptualised as the chance of an adverse, harmful or unpleasant event occurring and risk perception

22 This term is defined in the glossary on page 267.
involves the subjective judgment an individual makes regarding the characteristics of the risk (Palmer & Sainfort, 1993). The numeric risk figure constitutes one part of an individual’s risk perception. Many other factors are likely to be involved in how an individual makes meaning of that numeric risk figure. Individuals have different interpretations of any given condition and its burden. This is recognisable in both the interviews and in the genetic counselling clinic. Women who come from families where the women with cancer have died of the disease often have a different perception of the meaning of a cancer diagnosis than women who come from families where people survive their cancer diagnosis. A woman who was diagnosed with a high grade breast cancer aged thirty-four years noted that no one’s ever died in my family from breast cancer when she was recalling the disorientation of the days around her own diagnosis.

The complexity of risk interpretation is illustrated by this young woman who carries a BRCA1 mutation. She acknowledges that the risk of breast cancer is very high and gives a statistical probability. She goes on to qualify the risk for herself on the basis of her family history:

...my risk of breast cancer is very high, BRCA-1 it’s like 80% or something, but there’s no breast cancer in the family... [13].

Her mother and maternal grandmother both died of ovarian cancer and throughout her interview she is more concerned with the risk of developing ovarian cancer. Many of the women in the current study demonstrate that motherhood also has a significant impact on risk perception and management choices, as will be discussed in chapter seven.

Women give voice to their concern about their individual risk in a number of ways. A young woman with a BRCA1 mutation, says I’m just living with a time bomb, indicating that she perceives a diagnosis of cancer as inevitable and catastrophic. On the basis of her perception of the level of risk, she has chosen to have a both risk reducing bilateral mastectomy and salpingo-oophorectomy while still in her early 30’s. Another woman, who has also chosen to have these risk reducing surgeries says of her breasts I was starting to think these things are going to kill me... [29]. A number of women in the
group use the term “get rid of” to describe their feelings about their ovaries and the risk they pose. Hallowell (2000) used interviews with women considering bilateral prophylactic mastectomy to explore the idea that, for women from families with hereditary breast and ovarian cancer, breasts are viewed as “dangerous objects” and that one way to minimise the risk to oneself is to remove the site of danger from one’s body. The women in my study support this idea, using terms such as “time bombs” to describe their breasts and ovaries and talking about wanting to “get rid of those things”. I will discuss the impact of risk perception on decisions regarding surgery further in chapter eight.

5.4 Sources of information for decision making

*I think that if anything, you need to be an informed individual and I don’t think that you can make a wise decision unless you gather that* [3].

Information in some form has been a crucial influence in decision making for each of these women as they have come to understand the increased risk of cancer and as they seek to manage this. Many of the women voice a strong desire to be well informed about their risk, the ways to manage the risk and the advantages and disadvantages of each option. Their comments indicate that they want the health practitioners they interact with to treat them as intelligent women, able to make informed decisions. One woman, in the process of deciding to have a salpingo-oophorectomy in her late 40’s and concerned about the possibility of menopausal symptoms, says she has not

…”had a lot of information other than oh we can manage that, which doesn’t strike me as very informative. (Laughs) I want to know what’s going to happen” [1].

These women reflect a growing trend in health care for patients to seek their own health information, rather than accepting that the “doctor knows best” (Ziebland, 2004).

Women have differing levels of need for information, and this is well demonstrated by the participants in this study. Some women talk about doing extensive research, such as this woman who carries a BRCA2 mutation:
I’m a bit of a researcher on the, on the net. I mean I like to know about stuff and I find good websites that tell you about it, so I would have read all about it. So I’m an instant expert [14].

Other women recognise that they want some information but not too much, as is the case with this woman who has had breast cancer and uninformative BRCA mutation analysis:

I suppose I didn’t want to know too much. I wanted to know a little bit you know just enough to keep me informed [17].

The women were asked about their sources of information, with the conversation including questions about which sources they thought were most trustworthy. Three of the women did not name the specific sources of information but told the interviewer that they had enough information. Twenty-nine women named multiple sources of information. The most common sources of information were medical professionals, with twenty-five participants identifying at least one medical specialist as an important source of information. The specialists included breast surgeons, gynaecological oncologists, plastic surgeons and oncologists. Given the specialised nature of the information these women were seeking, it is unsurprising that few women mentioned their family doctor as an information source. The few women who did mention their family doctors primarily did so in terms of providing education for the doctor, rather than receiving information. Genetic counsellors were mentioned by sixteen participants as an important source of information. The letters that genetic counsellors write were specifically mentioned by eight women, highlighting their importance. They were mentioned either in the context of receiving a family letter telling them about the presence of the mutation in the family or as a resource that they return to, to remind them about certain aspects of their increased risk and the management.

The women interviewed for this study identified a number of medical professionals with whom they interacted regarding options for managing their increased risk of ovarian and breast cancer. Many of the women were seeing or had in the past seen at least one breast surgeon, a plastic surgeon and either a gynaecologist or gynaecological oncologist or both. The impact of engaging with multiple medical professionals was not explored, although on reflection this would have been helpful in understanding how this affects the decision making of this group, particularly if conflicting information is
received. A few women also mentioned sharing surveillance and risk management information, both with their sisters and with other high risk women they were in touch with.

*It’s sort of one person finds something out and we all start...* [28].

This comment was made by a young woman whose sisters also carry the MSH2 mutation that she carries. Interactions with multiple medical professionals and sharing information means that women may receive large amounts of information which they need to make sense of. Sheri Babb and colleagues (2002) found that many women making decisions about prophylactic salpingo-oophorectomy or ovarian surveillance found the process of gathering information frustrating and anxiety provoking. The volume and complexity of the information may well contribute to this sense of frustration. Babb et al (2002) noted the need to process this information within the context of a woman’s psychosocial needs and her cancer experiences and perceptions and suggested that genetic counsellors be aware of these needs when working with women to process this information.

Women mentioned a range of other information sources including the internet, friends and family members, other at risk women, a television documentary about a young women having risk reducing mastectomies that was televised during the period when I was recruiting, books, pamphlets, the newspaper and the Cancer Society.

### 5.4.1 The internet

Internet use is increasing rapidly. After health practitioners, the internet is the most commonly cited source of information, with eighteen women reporting using the internet. Four women reported that they had made a deliberate choice not to use the internet as a source of information commenting that

*I’d scare myself probably. I’d probably invent things going on, no I don’t do that, no* [8].

Ten participants did not mention the internet, although some of these women noted that they had done extensive research and it is possible that internet use was a part of this.
Approximately 80% of New Zealanders currently have internet access at home or at work, an increase of close to 60% since 2000 (Internet World Stats, 2008). People use the internet to look for health-related information for themselves and for friends and family members. In 2005 Hesse et al reported the findings of the first health information national trends survey (HINTS), which found that 63.7% of internet users in North America used the internet to seek health-related information. Health-related information searches are more common among people aged less than sixty-five years, women, and those with higher levels of education and income (Cotton & Gupta, 2004; Hesse et al, 2005; Pandey et al, 2003; Satterlund et al, 2003; Statistics New Zealand, 2008). Studies suggest that people use online health information as an adjunct to the information they receive from their health care providers (LaCoursiere et al, 2005; Sillence et al, 2007).

The women who participated in this study fit the demographic for internet users as they are aged between their early twenties and late sixties, twenty-eight of them reported that they completed secondary school and more than half of them have a tertiary education. They talked about using the internet in addition to seeking information from health practitioners.

*I did get given enough information but I also looked on the internet just because I like to make sure I’ve got all the information, yes* [4].

Researchers in this field recognise the need for health practitioners to engage with the internet as a source of information and support for patients and to work with patients as they access this material. There is some evidence from the women in the current study to suggest that this is happening. One of the women mentions that her gynaecological oncologist suggested a number of websites for her to look at and another woman talked about giving a genetic counsellor a website and subsequently hearing from other women that the genetic counsellor had given them information about this website. However, Roche and Skinner (2009), reporting the findings of a study of internet use by 100 families note that clinicians in genetic clinics rarely initiated discussions about internet use with families and did not always explore this topic when families talked about their experiences of looking for information and support on the internet. Taylor and colleagues (2001) also found that genetic clinicians seldom referred families to internet sites. Roche and Skinner (2009) suggest that the internet provides a forum for clinicians to extend their reach beyond the clinic visit and recommend that a discussion about
internet use and suggestions about sites to visit should become part of genetic consultations.

Changes in access and demand for control of health-related information date back to the women’s movement of the 1960s when people began to seek their own health information and to move away from the idea that the “doctor knows best” (Pandey et al, 2003). The internet provides individuals with a quick and easy way to collect health information and to make contact with and gain support from other people in similar situations (Ziebland, 2004). Contact with other BRCA-positive women has been an important source of information and support for several of the participants in this study. As described previously, a young woman who had a positive predictive BRCA test not long after testing became available in New Zealand talked about the isolation she experienced and her desperate need to talk to someone in a similar situation.

…it was very hard because I didn’t really tell anybody, didn’t tell any of my friends… I’m pretty much on my own in my family… [13].

More recently she made contact with two women who also carry BRCA mutations and described the ways in which they shared support and information, including sharing websites.

Some of the women in this group describe ways in which they are active participants in seeking information to allow them to make the best decisions possible to manage their risk. Eighteen of the women interviewed stated that they used the internet as a source of information, with some women describing doing extensive research, for example

*I’ve done heaps of research on the internet* [30].

Three women mention using the internet to check the validity of information given to them by doctors. One woman describes her own surprise at her surgeon’s surprise at the finding of an occult fallopian tube cancer diagnosed after her risk reducing salpingo-oophorectomy. She describes going home and looking it up on Google, only to find that primary fallopian tube cancer is relatively rare, saying

*So at that point I kind of went weak at the knees and thought no wonder he was so surprised* [7].
This woman also talks about looking up her BRCA mutation on the internet. The finding that women use the internet to check on information given to them by their doctors is supported by studies such as one by Pandey and colleagues (2003) who found that women are increasingly using the internet to supplement information from health care providers. Ziebland (2004) suggests that the ability to access health information on the internet allows patients to present themselves as informed and competent patients, able to question the information given to them by health practitioners, seek alternatives, and make autonomous decisions. Murray and colleagues (2003) found that families used the internet to increase their understanding of the medical condition and to facilitate their ability to communicate with health practitioners. These findings are supported by women in my study who discuss doing extensive research and reporting their findings to their doctors and specialists. One woman who did extensive research comments that her surgeon said

...in my letters to Southern Cross and things that I was very well educated on the topic [30].

The issue of whether to trust the information they found on the internet was raised by several women.

I don’t trust the internet for, well I would but I wouldn’t take it as gospel, it would all depend on what site I went into [1].

...you can get on to the internet but that’s a bit scary because you don’t know what’s up to date [7].

The issue of trust related to the vast quantities of information available on the internet has been explored in other studies (for example Hesse et al, 2005; Taylor et al, 2001; LaCoursiere et al, 2005; Sillence et al, 2007). Hesse et al (2005) found that their participants were divided on the issue of how much they trusted the internet as a source of health-related information, with about a quarter of their participants expressing a lot of trust and a quarter expressing little or no trust. They found that people with higher levels of education expressed more trust in information from the internet, perhaps because those people have skills in identifying reliable websites. Taylor and colleagues (2001) found that only 7% of their respondents felt that some of the information found
on the internet could not be trusted, suggesting higher levels of trust amongst their study population.

Sillence and colleagues (2007) investigated the way in which people decide whether or not to trust the information they find on the internet by following fifteen women who were using the internet to make decisions about the use of hormone replacement therapy. Their study supported a three-stage model of trust involving rapid sorting and rejection of sites, a careful interrogation of sites selected as potentially credible, before sites identified as trustworthy were used to generate and test personal theories about hormone replacement therapy use. This study suggests that women do consider trustworthiness when using the internet to seek health information and that they incorporate a number of aspects of website design and content when making decisions about which websites to use and trust (Sillence et al, 2007).

LaCoursiere and colleagues (2005) found that cancer patients trust online information obtained from sources that they viewed as reputable including journal studies, doctors and websites endorsed by health authorities. These studies, and the comments of the women in the current study, suggest that people consider issues of trust when searching for online health information and that, as a community of internet users, we are developing skills in accessing reliable sources of information online.

This study did not specifically ask women if they had access to the internet, but the issue of access was raised by one of the participants.

> I think I’m reasonably able to go on the internet and get all of the information that I need but I do wonder how other women who don’t have access to those sorts of resources… get to find out because you have to learn individually as you go [25].

Statistics about internet access demonstrate that access is increasing and the so-called “digital divide” is narrowing. As noted previously, approximately 80% of New Zealanders have internet access (Internet World Stats, 2008). As this woman comments, people have to learn how to search for information. Search engines such as Google and Yahoo return huge quantities of information when general search terms are used, and parents of children with genetic conditions have reported being over-whelmed by the amount of information a search can return (Roche & Skinner, 2009).
In summary, women in this study use a variety of sources when seeking information about living with and managing their increased risk of ovarian cancer. Medical specialists and genetic counsellors are primary sources of information for the majority of this group of women. Many women use the internet to seek information and support about inherited cancer risk. A few women reported understanding internet information could be inaccurate and indicated they used the internet with caution. With increasing access to and interest in using the internet to collect health information, health practitioners have an opportunity to facilitate internet use to ensure clients and families locate quality information.

5.5 Information for risk management

The BRCA genes were identified approximately fifteen years ago. Genetic counselling and clinical testing for BRCA mutations has been available for over ten years in New Zealand. As a result of the accessibility of testing internationally, an increasing number of women, including growing numbers of young women, are facing decisions regarding managing their breast and ovarian cancer risk. Many of these women have many years of active, healthy, young womanhood before them, years in which they will form new relationships, be sexually active, and perhaps have children. Women in this study and in earlier studies (Hallowell et al, 2004; Matloff et al, 2009; Meiser et al, 2000) have indicated the importance of receiving quality information and ongoing support as they explore the possibilities for risk management and make decisions about managing their cancer risk. This section explores the information needs of women contemplating risk reducing salpingo-oophorectomy and mastectomy.

The women interviewed for this study report receiving varying amounts of information about the effects of surgery from the medical professionals caring for them. Many women reported receiving quite limited information about the effects of an early surgical menopause from their doctors. As noted above, one woman had deferred risk reducing salpingo-oophorectomy and attributes her decision partly to her concerns about menopausal symptoms and to being “brushed off” when she asked for information. She is not alone in saying that she has not received enough information. Other studies have also found that women would like more detailed information and the opportunity for discussion prior to making decisions about risk reducing salpingo-
oophorectomy (Hallowell et al, 2004; Klitzman & Chung, 2009; Meiser et al, 2000). Ellen Matloff and colleagues (2009) report that many of the women seen in their familial cancer clinic in the United States have received very little, if any, information prior to surgery on the impact of premenopausal salpingo-oophorectomy on libido, body image and achievement of orgasm.

Some of the women interviewed for this study appear to have a limited understanding about the way in which their bodies work. One postmenopausal woman who has not had her ovaries removed and is in her late 50’s said that she would do so if she felt that she was at high risk of developing ovarian cancer. She goes on to say

...at my age now I’ve had my children so it wouldn’t matter at all. I mean I guess if I have my ovaries out I’m obviously on some form of hormonal thing to keep me from becoming a man. [32].

Her comment about becoming a man suggests a limited understanding of the way in which her body functions, with ovaries naturally ceasing to be involved in hormone production resulting in menopause. Her decision to retain her ovaries may have been made without an adequate understanding of the limited effect the surgery is likely to have for a woman who is postmenopausal. Another, younger woman also identifies her incomplete understanding of the function ovaries have in hormone production:

I mean I haven’t learnt about, I honestly had no idea about menopause. I actually thought that, and I guess that’s probably not having my Mum and that but I just thought lots of women have hysterectomies, I’ve heard lots of women and I thought well, what’s the difference, you know [13].

She had recently talked to another woman who carries a BRCA mutation and reported that she was shocked to learn that having her ovaries removed would precipitate menopause. Other New Zealand researchers have also identified limited understanding about menstruation and menopause, about the way in which their body functions, among women (Barker, 1999). It is concerning to think that women are undergoing irreversible surgery without fully understanding the potentially lifelong implications of that surgery.
The receipt of adequate information about the impact on body image and sexuality is also lacking for women making decisions about risk reducing mastectomy. Several women who had had risk reducing mastectomy were asked if they had been given information about the possible effects of the surgery on their sexuality and body image. None of the women could recall being given this information. Some women had found information through other sources, including on the internet, but not all women have access to this type of resource. One of the women, scheduled to have a risk reducing mastectomy a few months after her interview, was not sure whether she would still have sensation in her breasts after the surgery.

Women report that appointments with surgeons are incredibly nerve-wracking [16] and that they feel intimidated by the surgeon [29], and mention issues to do with body privacy, for example I’m just so sick of taking my top off and it’s just so degrading [27]. Surgical outpatient appointments in New Zealand public hospitals are generally brief, so women have very limited time to ask questions. Some of the women indicated that they felt that they needed to behave in a way that would suggest to the surgeon that they were a “deserving” candidate for risk reducing surgery, particularly in the case of mastectomy. One woman reported seeing the plastic surgeon regarding reconstruction once and subsequently realising that she had many unanswered questions. Her partner suggested that she

...write a list with all these questions down and contact them. And I said oh I’m scared if I ring up and say look at all these questions he’s going to think oh she’s having second thoughts or oh she’s not really ready. Let’s put the date off. I said I don’t want them to put the date off [29].

She was concerned about very pertinent and important issues, fundamental to her sense of self. One of her major concerns was that the plastic surgeon had not asked what cup size she wanted to be and she feared that he would decide this independently. While this issue was causing her significant anxiety, she did not feel comfortable asking for a second appointment prior to the surgery to discuss her unanswered questions in case the surgeon decided to cancel her surgery. She states that she feels intimidated by the surgeon [10]. This interaction highlights the inherent and deeply entrenched power
differentials that exist within the medical system, which impact directly on the ability of these women to obtain relevant and important information.

As part of my clinical role as a genetic counsellor in New Zealand, I have established a “family history clinic” for healthy women with an increased risk of breast cancer, run by a breast surgeon and a genetic counsellor. We have had a number of conversations regarding risk reducing mastectomy. The surgeon’s view initially was that women who are interested in surgery should initiate the conversation; however more recently she has started to raise the issue of surgery with women with BRCA mutations. She usually arranges a referral to a plastic surgeon for a discussion about reconstruction. I have not observed a conversation about the impact on sexual response and body image, and the women interviewed for this study support that observation, with one women saying no one really touched on that [30] when asked whether anyone had discussed the potential for changes in sexuality with her. Women having treatment for breast cancer also commented that there was nothing about what you might expect [25] in relation to changes in body image and sexuality. The fact that a woman who was booked to have a risk reducing mastectomy did not know whether she would have sensation in her breasts after the surgery is also indicative of a lack of discussion with women contemplating surgery.

5.5.1 Psychosocial aspects of care

I'd say the only thing that hasn't been offered to me is counselling [27].

Studies from overseas indicate that a significant number of women experience feelings of reduced sexual and physical attractiveness, altered femininity, and adverse changes in sexual relationships after bilateral risk reducing mastectomy (Brandberg et al, 2008; Bresser et al, 2006; Hopwood et al, 2000). In some countries the planning for surgery is done in the context of a multi-disciplinary team which includes social workers or psychologists (Bresser et al, 2006; Hopwood et al, 2000). In New Zealand referral to a psychologist appears to be suggested only to women that surgeons suspect may have difficulty with the outcome of the surgery, rather than being a routine part of clinical care. The belief that a surgeon can make an informed decision regarding whether or not a women should be referred for counselling during a brief surgical outpatients
appointment suggests an inherent power imbalance in medicine. It also highlights that the need for a referral for counselling appears to be viewed as a deficit in the woman concerned, rather than as a positive action that may contribute to a healthy outcome after surgery. The inclusion of an appointment for pre-surgical counselling would facilitate an opportunity for women to discuss the broader implications of risk reducing surgery than they are able to do with either a genetic counsellor or their surgeon. A broader discussion encompassing the possible implications for areas including the woman’s body image, identity and intimate relationships acknowledges that both oophorectomy and mastectomy have implications beyond the physical. In addition to a pre-surgical consultation, a post-surgical follow up appointment could be routinely available to address any unforeseen issues that have arisen since the surgery and that are not covered in a follow up appointment with a surgeon. The women interviewed for this study clearly indicated that the opportunity to talk through a number of issues related to the surgery in greater depth would be very beneficial to them.

Other women facing mastectomy are able to access psychological support. For example, women with breast cancer can access counselling, information and support through the New Zealand Cancer Society, whereas women contemplating risk reducing mastectomy may find it difficult to access support through the Cancer Society as they do not have cancer. Women undergoing gender reassignment surgery involving a bilateral mastectomy must see a psychologist as a mandatory part of their surgical planning (Ministry of Health, 2010). While the issues associated with gender reassignment are significantly different from those facing women with an increased cancer risk, it seems surprising that women considering risk reducing mastectomy are not at least offered counselling as part of their surgical planning. One of the women interviewed for this study mentioned that she had been to talk to a counsellor several times as part of preparing for the surgery, but the majority of these women did not have the opportunity to explore the possibility of significant alterations in the way they view their bodies and in their intimate relationships prior to surgery.

The question of who should be giving these women information about sexuality is a thought-provoking one. The majority of the women undergoing risk reducing salpingo-oophorectomy and/or mastectomy in this study are healthy, with the surgery done as a means of maintaining their health. Health-care is practiced within a society that is steeped with images of vibrancy, sexuality and intimacy. Research regarding health
practitioners talking about sexuality in oncology care provides some insight into the reasons that women considering risk reducing surgery may not be receiving adequate information about the impact on sexual functioning.

Sexual function and sexuality are vital aspects of our lives, yet they are generally not addressed in routine oncology care (Shell, 2006). Studies of health practitioners working with cancer patients reveal that many health practitioners struggle with knowing how to initiate a conversation about issues related to intimacy and sexuality (Hordern & Street, 2007; Katz, 2005; Lavin & Hyde, 2006; Lemieux et al, 2004). Health practitioners report lacking the time and privacy to discuss these issues with patients, and make the assumption that patients will raise the matter if they are concerned enough about it (Hordern & Street, 2007; Lavin & Hyde, 2006). In an exploratory study with palliative care patients in Canada, Lemieux and colleagues (2004) found that only one of the ten patients they interviewed had been asked about sexuality during their diagnosis and treatment. All the patients in this study indicated that they felt that this was an important aspect of life and should have been raised with them. Patients in an Australian study also thought that health practitioners should initiate a discussion about intimacy and sexuality, indicating that they were searching for strategies and support that would help them accept and live with the alterations their cancer treatment had wrought (Hordern & Street, 2007). Hordern and Street (2007) suggest that complex cultural factors are at work within health care systems which prevent health care practitioners from discussing intimacy and sexuality with patients, allowing them to maintain the “safe” belief that patients are asexual. Sexuality and sexual function may not be routinely addressed by women’s general practitioners either. Nappi (2007) suggests that women may not initiate a discussion about sexual functioning with their doctor, but that they are likely to be receptive if the doctor initiates a conversation.

Given the difficulties that oncologists, oncology nurses and general practitioners, all of whom are likely to see patients regularly during the course of their treatment, face discussing sexuality, it is unsurprising that surgeons working in busy outpatient clinics do not discuss this issue. The women in this study and in the studies by Hallowell et al (2004) and Meiser et al (2000) indicate that they would still choose to manage their risk surgically. What they are requesting is more information, information that is cohesive
or, as one woman suggests is current best practice and an opportunity to discuss this issue prior to the surgery.

The findings of this study, anecdotal reports by women attending Matloff et al’s (2009) service, and the findings of earlier studies (Hallowell et al, 2004; Meiser et al, 2000) indicate that these women would like information about the potential effects of premenopausal salpingo-oophorectomy on their body and their libido. They would also welcome the opportunity for discussion regarding the effects of risk reducing mastectomy on their body image, sexuality and identity.

5.6 Risk management

Perhaps the single biggest decision women make after learning that they have an increased risk of developing ovarian/breast cancer is how to manage their risk. Their options are to have increased surveillance aimed at the early detection of cancer or to have risk reducing surgery. Bilateral salpingo-oophorectomy very significantly reduces the risk of ovarian cancer, with a residual risk of primary peritoneal cancer of 1% (similar to the population risk of ovarian cancer of 1.6%) remaining after surgery (Kauff et al, 2002; Rebbeck et al, 2002). Premenopausal salpingo-oophorectomy has also been shown to reduce the risk of breast cancer by up to 50% (Rebbeck et al, 1999; Kauff et al, 2002). Bilateral risk reducing mastectomy significantly reduces the risk of breast cancer (Hartmann et al, 2001; Meijers-Heijboer et al, 2001). Again, the residual risk is similar to the population risk of developing breast cancer.

The women in this study talk about the decisions regarding management as a series of overlapping decisions, rather than as a single decision. They describe a process of fluid decision making, whereby decisions evolve and are made over time and may change as a woman gets older and her circumstances or life stage changes. Several young women talk about deciding to have surveillance while planning and completing their family, sometimes with the intention to have risk reducing surgery after childbearing. Other women describe approaching the age at which their mother was diagnosed as being a defining period in their decision making, saying things like:
...as I got closer to my mother’s age that you sort of almost became paranoid that it was, yeah that you were watching out for tiny totally unrelated sort of symptoms [6].

A small number of women begin to plan for a future diagnosis of cancer, for example a woman who was fifty at the time of her interview and who carries a BRCA2 mutation says:

_I haven’t had a breast mastectomy but what I have determined in my head is that the minute there is any, I mean I am under regular mammogram and I have a mammogram and I see a specialist twice a year. And the minute there is something they do a biopsy and if it’s cancerous and then both of them go_ [10].

For each major decision that a woman makes, there are a number of additional decisions that arise. For example, if a premenopausal woman decides to manage her risk of ovarian cancer by having risk reducing surgery, she needs to decide if she will use hormone replacement therapy. Certain types of hormone replacement therapy are associated with a small increased risk of uterine cancer so some surgeons recommend women consider having a hysterectomy at the same time as the salpingo-oophorectomy, to give them a greater choice of hormone replacement therapy options. Hysterectomy involves more extensive surgery and a longer period of recovery, Hormone replacement therapy is associated with an increased risk of breast cancer (Chlebowski et al, 2010), so she must also decide whether the reduction in breast cancer risk afforded by premenopausal salpingo-oophorectomy is such that she feels comfortable using hormone replacement therapy or not. Women also need to decide how to manage their breast cancer risk, and again, these decisions tend to be fluid and to involve a number of steps in the decision making process.

The women identify many factors that are important influences in their decision making about how to manage the cancer risk. These include the women’s age, whether or not she has reached menopause, her family history of cancer, whether she has completed her family, her desire to be there to see her children grow up and her feelings about her body and in particular about her breasts. Other influences include the options available for managing menopausal symptoms, whether breast reconstruction is available to her, the timing of the surgery and whether she can manage her family and employment
responsibilities around the surgery and recovery. The support (or otherwise) of people close to her including her partner, family and close friends is also influential in decision making. I will discuss some of these factors in this chapter, and others will be discussed in chapter eight, which explores managing the risk with surgery.

5.6.1 Risk reducing surgery

Surgery to remove the ovaries and fallopian tubes, and in some cases the uterus, by age forty is the recommended management for women at high risk of developing ovarian cancer (Daly et al, 2010; Domchek et al, 2010; Haber, 2002). All but one of the postmenopausal women in this study for whom risk reducing salpingo-oophorectomy was indicated has had her ovaries removed. Seven women have had a premenopausal salpingo-oophorectomy, and two women were about to undergo surgery. Eleven premenopausal women had not had surgery, with most of these women planning to have surgery when they had completed their family and were closer to age forty years.

The women identified a number of factors that influenced their decision to have surgery, including doing it for the children, the influence of the death of a close family member to cancer, wanting to live, receiving a recommendation by a medical specialist, understanding the limited efficacy of surveillance for ovarian cancer, retaining control of the timing and extent of the surgery, and seeing no alternative. Despite the potential difficulties associated with a premenopausal surgical menopause, a number of premenopausal women in this study did not see any alternative to having a salpingo-oophorectomy. One forty year old woman, who was booked for a hysterectomy and salpingo-oophorectomy a few weeks after her interview clearly described the feeling of having no alternative when she said *we both know it is major surgery but you just have to do it* [27]. Another woman also noted the fact that she felt that there was no alternative to surgery when she said

...maybe I should be more melodramatic but to me I didn’t think there was a choice if I wanted to reduce the risk [19].
For the woman who had predictive testing for a BRCA1 mutation almost a year after receiving a letter from a research consortium, the motivation was related to her mother’s illness. She said

_I always said if it’s positive I’m definitely having my ovaries out, there’s no question about that. We watched Mum die_ [29].

She talks about how, after receiving her result _I just wanted those things out_ and she was _rapt_\(^{23}\) when the gynaecologist was able to perform the surgery six weeks after her initial consultation with him. For other women, the motivation is related to their own children, for example a forty year old woman with two primary school aged children says

_I think maybe that was more my driver there as I want to be here to see them grown up and everything_ [30].

The woman who commented that perhaps she should be more melodramatic about having a risk reducing mastectomy in her early thirties says

_I just did it for the kids. I want to be around to see my kids grow up_ [19].

Throughout the interviews there is a strong drive to survive, both for one’s children and also for oneself. A woman who was in her late thirties at the time of her interview and who was still contemplating whether or not to have children sums up this feeling when she says

_I just didn’t want to die of cancer_ [16].

The decision to proceed with a salpingo-oophorectomy is driven by recommendations from medical professionals in some cases. Most of these women demonstrated a clear understanding that surveillance for ovarian cancer was not effective, saying things like

_…after a while I started to feel uncomfortable that the monitoring for ovarian cancer was not very, well I couldn’t guarantee that it was_

\(^{23}\) The word “rapt” is defined as meaning spellbound or totally engrossed; however this word may be used colloquially in New Zealand to mean excited, relieved and happy, as is the case with this woman’s use of the term.
going to be very successful and so eventually I decided to explore having an oophorectomy... [6].

A number of these women were told by their specialist that they should have a salpingo-oophorectomy. One woman recalls her specialist saying that really isn’t a choice because ovarian cancer is such a lethal one [27]. A number of other women make similar comments about receiving recommendations from their doctors. A woman who was in her early sixties when she saw a gynaecologist to discuss the possibility of salpingo-oophorectomy also sought support from her GP for the decision:

She said well you know you’re not ever going to have children again because I’d had a hysterectomy and she said you’re through the menopause, it’s not going to make any difference to you in any way because your ovaries would be just about useless now anyway [11].

While the majority of women interviewed had either had their ovaries removed or were planning to have surgery when they had completed their families and were close to the recommended age of forty, a few women acknowledged that they were prepared to defer surgery for a period of time. A forty-seven year old woman who was diagnosed with breast cancer in her thirties and with a contra-lateral breast cancer in her early forties had been found to carry a BRCA1 mutation several years prior to her interview. She deferred having a salpingo-oophorectomy until closer to the time when she would naturally be entering menopause:

I’ve, up until now I’ve chosen not to have my ovaries removed but I’ve just made the decision to do that and I’ll probably have them taken out in the next couple of months. No probably, probably the only thing I would say is my main worry about the ovarian side of things was going straight into menopause and I don’t, haven’t had a lot of information other than oh we can manage that, which doesn’t strike me as very informative. (Laughs) I want to know what’s going to happen. But I figure now I’ve reached an age where I could probably live without them [1].

The opinions of one’s family and close friends may play a part in decisions about how to manage risk. Women in this study voice concern about the impact on their family.
When talking about her plans to have a salpingo-oophorectomy in her mid thirties, one woman says

...the biggest fear of having an oophorectomy is that I would turn into a monster and I think that is my husband’s fear too [19].

Another woman also mentions the potential impact of surgery for her partner

And I mean yeah there’s the sexual thing you know… So he’s got to be comfortable with it as well [27].

This group of women usually go on to justify their decision by saying that their family would rather have them there than not. Hallowell (1998) interviewed a group of women at high risk of developing breast and ovarian cancer and suggests that family (biological family members, partners and children) influence women’s perceptions of risk management options. The women in her study talked about the consequences of surgery for other people as well as for themselves, suggesting that they balanced their own needs with those of others.

These Pakeha New Zealand women seemed to recognise that the decision to have a risk reducing mastectomy may be viewed as more “controversial” than the decision to have a salpingo-oophorectomy. Two of the women talked about being very careful about who they told about their decision to have a mastectomy, whereas none of the women mentioned this in relation to having a salpingo-oophorectomy. Two women in my study commented that they had been told by family members (in one case a sister and in the other case a father) that risk reducing mastectomy was too drastic a step to take.

I've had a lot of negativity from my father and the rest of the family… Mutilation as they call it. … they've just said oh if you felt you were going to get cancer in your arm would you cut your arms off? So that's been really hard to deal with and trying to reason with them [27].

Despite this opposition, they both went ahead with the surgery, reporting that being there for their own children was a strong motivating factor in the decision. Both women had supportive partners.
5.6.2 Surveillance

Many of the women were having surveillance aimed at early detection of one or more types of cancer. A number of the women were having surveillance for breast cancer, several women were having CA125 measurements and ovarian ultrasound, and a few women (from families with Lynch syndrome) were having regular colonoscopies. Women reported a number of factors influencing their decision to have surveillance. Many of the younger women were having surveillance while deciding whether or not to have children and while they were in the process of completing their families. They articulated their reasoning and planning as follows:

\[ I'm \text{ getting rigorous preventative plus monitoring } \ldots \text{ my plan with [doctor] is to finish my family and then in my late thirties think about having my ovaries out } [13]. \]

\[ I \text{ mean if I made decision tomorrow that I wasn't going to have children and I was 100\% sure I would have that surgery } [16]. \]

Other women described feeling comfortable with having surveillance for some types of cancer. One young woman, who was still completing her family and who said that she planned to have her ovaries removed after her family was complete, said

\[ \ldots \text{breast ultrasounds plus MRIs is a screening option and to me six monthly screening sounds pretty good } [3]. \]

The family nature of hereditary cancer and the complex interactions that sometimes arise in families as a result of genetic risk assessment and genetic testing extend into the area of surveillance, just as they may also influence risk reducing surgery decisions. Parents of adult children commented that their offspring had a chance to alter the course of a diagnosis by having regular surveillance and made comments about wanting to make sure their children had regular screening. For example, a woman who was diagnosed with colorectal cancer in her 50’s and comes from a family with Lynch syndrome understands that regular colonoscopy reduces the chance of a diagnosis of colorectal cancer and says

\[ \ldots\text{certainly my children will be screened regularly... I will be on to them to make sure they do regularly } [21]. \]
5.7 Telling/Not telling

Some members of my family have come out and said I’ve got it and some haven’t and they’ve kept it to themselves [16].

The issue of who to tell about the increased risk of cancer, how much to tell them, and when to tell them, arises in all of the interviews. The comments are made in relation to three distinct groups of people; family (adult blood relatives), children (young children and teenagers rather than adult children), and friends. Telling adult relatives and friends is discussed in this chapter, while talking to children about inherited cancer predisposition is discussed in chapter seven.

5.7.1 Families

Families are unique and complex entities. There are a range of ways in which researchers define families, including families of choice, families of marriage, and families of origin. These groups of individuals may share some genes, they may have shared an environment while growing up, and they may or may not share the same values and belief systems. For the purposes of the discussion I am undertaking, the word family is used to refer to a group of people who are genetically related to one another. Some families are close and share information easily both within small family groups and within the larger extended family, while for other families, this may be more difficult.

When they found out they gave me a letter that I could hand out round the family which I did into the extended, it’s awful actually we had a family reunion not long after and I went down armed with this letter and I just couldn’t hand it out because there was another, another couple there who had a another genetic problem and he was actually dying from it on the other side of the family and so oh I can’t do this. So I did hand it out discreetly but I didn’t make any grand announcement that they should be doing this and I think some of them are slowly... [1].
Anyway we kind of lost contact with her [a cousin] and then last year she gave us the letter about the gene clinic from [Genetic Counsellor] to say that she had tested BRCA-2 positive and she just wanted to let us know. It was up to us what we did with that information [30].

Genetic counsellors regularly discuss the issue of informing the wider family with individuals who are undergoing mutation analysis, and often provide a general letter that can be passed to family members (Claes et al, 2003; Dugan et al, 2003; Suthers et al, 2006). Several women in this group talked about having the letter to pass on or about receiving a family letter notifying them about the mutation.

The dissemination of information about hereditary cancer appears to occur relatively frequently among first degree relatives, (Claes et al, 2003), particularly when families have relaxed and open communication patterns. As the comments above suggest, communication with more distant relatives can be problematic, particularly when families have lost contact with each other. Researchers exploring the matter of informing at risk relatives have found that people are usually willing to inform their relatives, but they may not always do so very successfully due to limited communication pathways and an incomplete understanding of who in the family should be informed (Claes et al, 2003; Gaff et al, 2005). Strategies such as discussing informing the family, providing general letters for people to hand on to their families, and offering to send these directly to relatives where the law permits are used as means of assisting with communication in families (Gaff et al, 2005; Suthers et al, 2006).

5.7.2 Friends

During the interviews, the women were asked about their sources of support, including whether they had talked about their increased risk and management choices with friends. Several women indicated that it was difficult to discuss their situation with friends as they often did not understand the risk and the implications well enough to be supportive. One woman described her distress at the lack of support from close friends when she told them she was having a pre-menopausal salpingo-oophorectomy:

*I chose a small group of my closest friends and thought these are the group I will tell. I emailed and said, well they knew that I had the gene*
anyway but I emailed them to say this is the surgery that I’m having and this is what’s going on. And my two very best friends, never heard from, never heard from, never heard from… [29].

The difficulty with explaining the situation and gaining support from friends can result in feelings of isolation and loneliness, as with a woman who had a risk reducing mastectomy without telling any of her friends or her extended family and who says:

It’s actually been better not to say anything and that’s been a hard thing because there’s been lots of people that I’ve kept myself away from because it’s been hard to have an ordinary conversation… [16].

Another young woman, who was one of the first women in New Zealand to have a positive predictive test, also describes the feeling of isolation the knowledge of her BRCA-positive status lead to:

I guess I felt just alone because one of the big things I was saying to [Genetic Counsellor] is I need to talk to somebody. Who else has this? And there wasn’t a lot of people at that time… I just felt desperately alone. And when I met her [another woman at increased risk], I met at the [cafe], and I looked at her and I saw myself. Just the anxiety, the, yeah the anxiety, the fear, you know? [13].

One woman had the experience of an extended family member telling a number of people in her local community about her risk reducing mastectomy and talks about the negative reaction she experienced:

As soon as I got out of hospital people that my father-in-law had told were very opinionated about why I had had it done and that they wouldn’t have done it etc which made me very angry as they didn’t know the risks and stats and at the end of the day it was my decision. I guess this is why I didn’t tell many people too because I had made up my mind and didn’t need anyone else’s opinion on my decision [19].

Genetic counsellors, support groups and internet groups may all have a role in helping women to find a safe forum to talk about their risk and the management options. The finding that one carries a BRCA mutation can result in a period of distress (Meiser et al,
and risk reducing surgery and the consequent losses a woman experiences are all things which it may be helpful for her to discuss in a supportive environment. It is clear from the comments these women are making that they may not be able to access this support from their friends, in which case it is important that genetic counsellors and other health practitioners introduce them to any available supports, such as internet or local support groups. Women also commented that it can be helpful to have contact with other women who have an increased risk. Again, this can be facilitated through the genetic clinic. Genetic counsellors explore a woman’s support systems when they are discussing genetic testing for BRCA mutations. Given these comments about difficulties that women have encountered when telling friends about their risk, it may also be helpful to mention that some women have experienced negative reactions, so that women can think about who they will tell.

5.8 Prenatal decisions

…if you know my sisters and I do have kids it affects them and it affects whether we decide to keep the baby or not necessarily you know. We can get them tested… my sisters and I, have sort of decided that we wouldn’t have a child with it [28].

Evolving technology is resulting in ever more complex decisions for people with inherited conditions. Prenatal diagnosis and pre-implantation genetic diagnosis are both theoretically possible for hereditary cancers. Pre-implantation diagnosis has been used by people who carry mutations in some hereditary cancer genes, for example in the APC gene associated with Familial Adenomatous Polyposis (FAP) (Moutou et al, 2007). Several couples in this study reported that they did not consider prenatal diagnosis and pregnancy termination an acceptable option, but they did consider pre-implantation diagnosis acceptable. The views of BRCA mutation carriers regarding the use of pre-implantation diagnosis were sought in a questionnaire study done in the United Kingdom recently, shortly after the United Kingdom Human Fertilisation and Embryology Authority (HFEA) approved the use of pre-implantation diagnosis for hereditary breast and ovarian cancer (Menon et al, 2007). This study found that the majority (75%) of women who carried a BRCA mutation (50% of whom had had breast cancer) supported the availability of pre-implantation diagnosis; however significantly
less than 50% of these women would have considered using it themselves. A number of
the women surveyed wrote extensive comments regarding their concerns and fears
about the use of pre-implantation diagnosis for BRCA mutations, including questioning
the value of their lives and noting concerns about the direction science is taking us
(Menon et al, 2007). Clare Williams and colleagues (2007) explored the views of staff
working in and associated with units offering pre-implantation diagnosis in the United
Kingdom just prior to the HFEA report approving pre-implantation diagnosis for late
onset, lower penetrance conditions. Staff identified complex clinical, ethical and policy
dilemmas but ultimately recognised that couples seeking pre-implantation diagnosis will
have their own perceptions of the seriousness of the conditions and felt that they needed
to recognise these.

Prenatal diagnosis for a known BRCA or mismatch repair gene mutation is also
possible, using chorionic villus sampling at about eleven weeks gestation. For this
thirty-eight year old woman, who is still thinking about having a family and has looked
at both options, the decision is complex.

…the pre-implantation testing which is still a bit new and it sounds like
you’re taking cells out at such an early age and it sounds too risky and
the other one which is chorionic villi testing which is sampling at about
ten or twelve weeks. What do you do once you know? It’s been a very
hard time really thinking about what to do…

Her question what do you do once you know? gets right to the heart of the matter. Do
you continue the pregnancy knowing the risk for an adult onset condition or do you
choose to terminate the pregnancy? These questions are beyond the scope of this thesis
but warrant further research and discussion as there are likely to be increasing numbers
of requests for prenatal diagnosis and pre-implantation diagnosis as genetic testing for
hereditary cancer becomes more commonplace.

5.9 Conclusion

This is the first study to look at New Zealand women’s experiences of being at
increased risk of breast and ovarian cancer. Many of these women are also at increased
risk of breast cancer. The women interviewed for this study describe similar experiences
to their overseas counterparts when discussing their family history of cancer and the risk assessment process they have been through. They report similar frustrations with provision of information and comment that they would have liked to receive more detailed information about their options and in particular about the implications of each risk management option. In particular, these women report receiving little information about the effects of a surgical menopause when considering pre-menopausal risk reducing salpingo-oophorectomy.

The decisions these Pakeha New Zealand women are making and the factors that influence their decisions are also similar to those made by women overseas. Throughout the interviews the presence and influence of their families is clearly felt. The defining feature of the interviews is that of attitude, with the majority of women exhibiting a resilient and pragmatic attitude to living with and managing their risk. The belief that one needs to “just get on with it” is strong for many of these women. I suggest that it is this feature that is predominant among Pakeha New Zealand women and I will discuss this in detail in the following chapter.
Chapter Six

Ways of approaching risk: The experiences of a group of New Zealand women

I am a woman, I have a big life
A mother, a daughter
My lover’s widowed wife
These things are so much bigger than
The enemy that lives within
The shadow underneath my skin
Is not the sum of what I am.

(From: The sum of what I am, by Julie Matthews. Together Alone Chris While and Julie Matthews, Circuit Music, 2008)

In the previous chapter I discussed the process of finding out about being at increased risk of developing breast and ovarian cancer and the many decisions the women who participated in this study make as they seek to manage their risk, communicate with their families and get on with their lives. The women all face similar decisions with regard to the options for managing the risk of developing cancer, and choosing who to tell both about the risk and about their choices for managing that risk. Each woman brings different influences to bear in her decision making, influences such as her experiences of cancer in her family, her life stage, and her feelings about the different risk management options. In this chapter I explore the ways in which the women approach their risk, their feelings or attitudes towards being at increased risk and the societal, political and cultural discourses that influence their approach.

These women are very clear that being at increased risk of developing cancer is only one part of their lives. First and foremost, they are women, wives and partners, mothers, daughters, sisters, friends and colleagues. While the quote above was written for women living with HIV, it encapsulates the essence of the interviews with these women who
are living with a risk of breast and ovarian cancer, a risk that also “lives within”. Time and again, these women tell us that they are just “getting on with” their lives.

*I'm not going to make it my life* [1].

... you just get on with it and so yeah that’s how we’ve always decided to deal with it [28].

Comments like this are scattered throughout the majority of the interviews, powerful affirmations of these women’s determination to do what they can to manage or reduce their risk of getting cancer and then to get on with living their lives because, in the words of one of these women, *living is the purpose of life... It’s that simple* [9]. These women are telling us that they are going to get on with their lives, that they will make tough decisions and that they will live with those decisions. They tell us that they want to live; they want to be there for their children, they want to watch their children grow up, and they are prepared to make difficult decisions and go through major, sometimes disfiguring, surgery to make that happen. These women are resilient and strong. They have often lost close family members, mothers, sisters and aunts, to breast or ovarian cancer. They have coped with those losses and now they are coping with managing their own risk.

Alaszewski and Coxon (2008) note that an individual’s response to uncertainty is grounded in their own experiences, cultural perceptions and dispositions and sometimes results in people making decisions that may be viewed as non-rational. Living with an increased risk of developing ovarian and breast cancer creates uncertainty, uncertainty about whether they will develop ovarian cancer and when this will happen, uncertainty about the efficacy of surveillance aimed at early detection of ovarian cancer and uncertainty about the effects of premenopausal risk reducing salpingo-oophorectomy. The Pakeha New Zealand women interviewed for this study approach these uncertainties in ways that appear to be grounded in their experiences of cancer in themselves and their close family members and their understanding of the dominant expectations in New Zealand society.

New Zealand women interviewed for this study expressed a number of different approaches to managing their risk. The predominant approach is to “get on with it”, perhaps a way of approaching life that is common to New Zealanders as a group.
Listening to and reading the interviews, I am repeatedly struck by the optimism, strength, resilience and desire to deal with the risk at a practical level so that the women can “get on with” the rest of their lives. The women identify ways of approaching their risk that support the notion of “getting on with it”, for example, determination and a desire to fight, choosing not to worry, and choosing to use surveillance or risk reducing surgery to help them feel safe. I suggest that the desire to “get on with it” is a characteristic of New Zealand culture and society for women, and that these women are bringing cultural and societal influences to bear in dealing with their increased risk of developing breast and ovarian cancer.

It is reassuring that the majority of women interviewed for this study are clearly indicating that they are not letting the increased risk of cancer stop them from getting on with their lives. However, there are a small number of women who appear to struggle with living with the increased cancer risk. These women talk more about their worries and fears and less about their determination to do what they can to reduce their risk. For genetic counsellors, there are lessons to be learned from the women who struggle with the increased risk – the women who are less able to “get on with it”. These women are likely to need ongoing follow up and support as they adjust to living with the increased risk.

6.1 “Getting on with it”

The majority of the women interviewed for this study speak in a generally optimistic and matter of fact way about living with risk and about the choices they have made, or are making, to manage their risk. Even when these choices involve risk reducing mastectomy or premenopausal salpingo-oophorectomy and subsequent premature menopause they speak positively, sometimes joking about the side effects of the surgery and the way they are managing these. The partner of one woman, who had recently had a salpingo-oophorectomy aged thirty-nine, had rigged up a remote control switch for the fan in their bedroom so that when a hot flush hits in the night she could just hit the switch, cool down, and then turn it off again. Other women talk about just trying to tough it out [4] or describe how they sort of like bumbled through [26] as they managed an early and abrupt menopause without using hormone replacement therapy. The message from these women is that they want to be “normal”, they want to be there to
watch their children grow up, they want to manage their risk and then they want to *get on with my life* [10]. The woman with the remote controlled fan perhaps sums up this feeling best when she says

*I think bravery’s got nothing to do with it; it’s about saving my life…* [30].

While it is possible to identify individual comments that highlight this feeling of pragmatism, matter-of-factness, and desire to “get on with it”, it is really the overall tone of each interview that defines which group a woman falls into. These interviews are scattered with comments such as:

*I just got on with it* [2].

*I got on and did it…* [10].

*I just get on with it* [19].

*I just seemed to get on with it* [21].

*… you just sort of have to go oh okay just get on with it…it’s something that’s happened and it’s not great but you just get on with it…* [28].

Sometimes phrases about “getting on with it” are repeated several times during these interviews. These women talk in ways that suggest they have a clear purpose and goal in mind. The goal is survival and they are prepared to take practical measures to achieve this goal.

### 6.1.1 “Getting on with it”: the emergence of a theme

The notion of pragmatism, matter of fact-ness or “getting on with it”, arose very early in the research process. After the first four interviews the contracted interviewer commented that she was concerned that the interviews would not contain enough material for the project saying “I’m quite surprised how “pragmatic” people are, not quite fatalistic but they do what they can and get on with their lives, basically!” (Email from A. Gray, 18 Dec 2006). During the initial analysis of the transcripts I noted the terms pragmatism, sensible and “get on with life” next to many of the statements in the transcripts. One of my supervisors then looked at six transcripts and used the term
pragmatism to describe comments such as *I’m not going to make it my life* [1] and *I wasn’t doing it for vanity, I was doing it to save my life basically* [30].

The matter of fact or pragmatic approach to their cancer risk that many of these women articulated was initially surprising, however it quickly became recognisable as the way in which many New Zealanders approach life. As Caroline Lintott, a genetic counselling colleague, commented early in the research process “I don’t know why you are bothering, most people just get on with it”. There are examples in the New Zealand media that reflect the desire to “get on with it”. For example, in an interview about her movie “Home by Christmas”, Gaylene Preston comments that her parents’ generation “took one day at a time and just got on with it.” (Thomson, 2010, p.13). The stories in Rachel Goodchild’s (2007) book about New Zealand women living on the land also contain a strong element of “getting on with it”, as women talk about their experiences of living in remote areas of New Zealand. As a researcher, the pertinent question is what it is about New Zealand women that results in a desire to just “get on with it”.

6.1.2 “Getting on with it” and risk reducing surgery

While the overall tone of each interview tends to indicate whether a woman falls into the group whose approach is more pragmatic, there are some specific topics that arise in the majority of interviews where the pragmatism can be seen most clearly. The issue of risk reducing salpingo-oophorectomy is one of the topics where many of the women make very matter of fact remarks. A woman who was perimenopausal at the time of her salpingo-oophorectomy says *... I didn’t think I would really miss them… [4]* of her ovaries. Another woman, in her early 40’s at the time that she learnt that she carried a BRCA1 mutation says *I just wanted those things out* [29]. Aside from the benefit of risk reduction and peace of mind associated with salpingo-oophorectomy, a few women mention other benefits including no longer having periods, the opportunity for a breast reduction (for a woman having a risk reducing mastectomy), and the feeling that having had the surgery gave closure to the risk, that they have done everything they can to reduce their risk. The finding that undergoing risk reducing surgery can give women a sense of comfort from having done all that they can to reduce their risk and be there for their children was also reported by Kenen et al (2007).
I also wanted to be in control of when I had/have my surgeries not have to wait and develop cancer and then have to have surgery – it is then out of my control [16].

*I mean it’s all about balancing things up because the worst case scenario for me would be to get breast cancer in the other breast and have to go through chemotherapy again, have my lymph nodes impacted, whereas if I have it out, if I have my other breast off under my own terms it’s in my own control in terms of timing, in terms of what I have done. I don’t have to get the lymph nodes interfered with which is what’s caused the greatest problem on the other side under the arm. You can get reconstruction at the same time and you don’t have to go through all of that chemo radio crap. So it’s a balance [9].*

Two women stated that being able to plan their risk reducing mastectomy and reconstruction allowed them to feel in control in a way that they thought was unlikely to have happened if the surgery had been as a result of a breast cancer diagnosis. Another woman who had had breast cancer and was planning a contra-lateral mastectomy also indicated that a feeling of control came from being able to plan the timing and extent of the surgery and particularly from the knowledge that her lymph nodes would be undisturbed.

A number of studies of women in Western countries have identified the importance of being able to act to control their risk to this group of women. Sheri Babb and colleagues (2002) found that women making decisions about risk reducing salpingo-oophorectomy reported the need for a feeling of control, both over the possibility of developing cancer and also over the decision making process. Hallowell et al (2004) interviewed twenty-three women who had had premenopausal salpingo-oophorectomy and found that all these women reported benefits to having risk reducing salpingo-oophorectomy including reducing risk and providing peace of mind. The women in Babb et al’s (2002) study also identified peace of mind as a benefit of risk reducing surgery. A feeling that knowledge was powerful and allowed them to confront their cancer-related fears and take control of their risk was reported by both Canadian and Australian women in separate, interview-based studies (D’Agincourt-Canning, 2006; Lim et al, 2004). These studies and the findings from the current study suggest that the means to feel an element
of control is important to many women who live with an increased risk of cancer. In the current study, the identification of a need for actions to help control the risk is associated with comments and behaviours indicative of a “getting on with it” approach to the risk.

Three of the women in the group have a mutation in a gene associated with an inherited cancer syndrome called Lynch syndrome or a clinical diagnosis of Lynch syndrome based on family history and screening test results. Women with Lynch syndrome have an increased risk of developing uterine cancer, ovarian cancer and colorectal cancer. One of these women perhaps sums up the attitude towards risk reducing surgery of the majority of women interviewed when she talks about managing her risk of uterine and ovarian cancer and says

“No, couldn’t get it out quick enough. I thought, if that was a site for cancer, take it out, it’s served its purpose [21].

Four women in the group have opted for risk reducing mastectomies and a further two women were due to have the surgery within a few months of the interview. Those who have opted to have risk reducing mastectomy speak about the decision in a very straightforward and pragmatic manner. They talk about how they …didn’t want to die of cancer… didn’t want to live with that anxiety [16]. They also talk about wanting to be proactive and … just to move on [27]. One woman, aged forty, was able to arrange to have both a bilateral mastectomy and a salpingo-oophorectomy performed at the same time. She talks about her decision saying I had actually no qualms about it whatsoever [30].

The women who had had risk reducing mastectomy at the time of their interview had all had their surgery within the past twelve months. At the time of the interviews, they all commented favourably on the decision to have surgery, although they talked about difficulties with healing and recovery that meant that they had moments when they wondered whether they had made the right decision.

But unfortunately on this one my incision line that goes from where the nipple was down opened up when they took the stitches out so I’ve only just finished with the district nurses yesterday… So yeah I’ve been having that dressed every week, several times a week…
Yeah but I mean because there’s no feeling there’s no pain. They kept saying to me does that hurt, does that hurt, and I go no… Yeah and I ended up on antibiotics a couple of times for infections, just staff infections but nothing major or anything like that [30].

...on the bad days, my breasts feel kind of like rocks and I feel pretty awful. I think sometimes I wish I hadn’t done it [16].

There are a number of factors that might influence how women feel after risk reducing mastectomy, including the length of time since the surgery and whether they have resumed sexual relationships with partners. Lloyd and colleagues (2000) interviewed ten women who had undergone risk reducing mastectomy in the previous three years. A number of these women experienced post-operative complications which necessitated readmission and sometimes further surgery. Despite these complications, most of these women did not regret the decision to have the surgery. In contrast, Payne and colleagues (2000) interviewed nineteen women, who had undergone risk reducing mastectomy some years before the interview and found that these women had a number of regrets about their surgery, including experiencing problems with their reconstruction requiring further surgery, difficulties with pain, and diminished self image and sexual satisfaction. In a study of archived messages on the Facing Our Risk of Cancer Empowered (FORCE) website, Kenen and colleagues (2007) found that women experienced tension between the expected relief the risk reduction associated with risk reducing mastectomy would bring and the stigma associated with choosing surgery that is regarded by some people as akin to mutilation. While the women interviewed for this study are expressing a favourable and matter of fact view of the surgery at this stage, it would be of interest to know if this approach continues over the years.

6.1.3 “Getting on with it”: societal expectation?

Other studies by and about women have identified “getting on with it” as a way of approaching different life experiences, indicating that it may be a gendered expectation for women. Kenen et al (2003) found that an attempt to “get on with their lives” was a common thread in interviews with twenty-one women attending a genetic clinic due to a family history of cancer. They suggest that this is an adaption to living with chronic
risk. Gail Darke (1996) interviewed a small group of women about the experience of menopause and noted that these British women regarded menopause and the accompanying symptoms as a natural life stage and something that one just got on with. Darke (1996) suggests that “getting on with it” may therefore be a societal expectation for women. In another British study, comparing women’s experiences of finding a breast lump or having a lesion identified during routine screening mammography, Sara Morris (1999) noted that “getting on with it” appeared to help many of these women cope with issues including selfhood, risk and uncertainty, and to get on with the treatment and then with their lives. Morris (1999) suggests that this attitude is part of a much larger health discourse regarding individual responsibility for managing one’s own health risks. Finally, in a recent study exploring the experience of gynaecological cancer Roberts and Clarke (2009) note that a woman in their study talked about having to “get on with it” as part of her discussion regarding trying to understand why she developed cancer. Roberts and Clarke (2009) suggest that this comment reflects a process of adjustment to the diagnosis and orientation towards the future. They make the temporal nature of “getting on with it” more overt than the analysis by Morris (1999), although the orientation towards the future can be seen in her description of women getting on with treatment and with their lives. These studies were all conducted in the United Kingdom. Perhaps the dominance of approaching risk by “getting on with it” identified in this New Zealand study is at least in part associated with New Zealand’s history as a colony of the British empire. The relationship between the studies from the United Kingdom and this New Zealand study encourage particular consideration of the overlay of cultural expectations along with gendered expectations.

The New Zealand women interviewed for the current study approach their risk management with a future orientation, expressing their desire to “get on with” managing or reducing their cancer risk to save my life and move on. As will be discussed in chapter seven, many of the women with young children expressed a strong motivation to see my kids grow up [19]. I would argue that the expectation that women will “get on with it” is far more pervasive an expectation than the studies described above appear to suggest. While the future orientation and the desire for a healthy future can be seen in all the studies, there is also a sense from some of the women in this New Zealand study and in the study by Morris (1999) that this attitude is socially expected. In order to be deserving of appropriate medical care and treatment, a woman must take personal
responsibility for her own health and must be prepared to “get on with” whatever treatments are deemed necessary. Morris (1999) reported that the women in her study justified their “right” to treatment for breast cancer by explaining that they had been following public health messages regarding mammography and breast self examination when they were diagnosed. The women in the current study also justify the acceptability of their risk management through a discourse of personal responsibility.

The discourse of personal responsibility is being discussed in the genetic counselling and sociology literature as well as in the public health domain (for example: Hallowell, 1999; Koch & Svendsen, 2005; Petersen, 1998; Petersen, 1999; Steinberg, 1996). In writing about her own experience of breast cancer, Dorothy Broom (2001) notes the stigma and secrecy that may surround the diagnosis and goes so far as to suggest that the “achievement of health has become a kind of social duty” (p. 254). In other words societal expectations are of health and vitality, and individuals are expected to take responsibility for maintenance of their own well-being. This may be particularly so for women given their responsibilities as care-givers of both children and other family members.

In an analysis of genetic consultations for hereditary breast and ovarian cancer, Hallowell (1999a) reported that the clinicians presented the risk of cancer as something manageable and indicated that women have a responsibility to act in ways that will manage this risk. In the year following their consultation the majority of women who took part in Hallowell’s study underwent risk reducing surgery, suggesting that they took on board the implicit messages regarding personal responsibility. Several commentators have suggested that the discourse of the genetic clinic implies that the people who come to the clinic are responsible for taking steps to manage their risk (Petersen, 1998; Petersen, 1999; Steinberg, 1996). The application of this discourse can perhaps be seen most clearly in the familial cancer clinic where surveillance and risk reducing surgery are routinely discussed but the option of “doing nothing” is seldom mentioned.

The place of personal responsibility has also been explored in other genetic clinic settings. For example, in her book examining the place of amniocentesis in American society, Rayna Rapp (2000) suggested that refusal to undergo prenatal screening could be seen as a refusal to manage one’s genetic risk. Deborah Steinberg (1996), also
writing about prenatal diagnosis, points to tensions between female agency and the prevailing medical discourse. As a consequence, the prevailing discourse of taking personal responsibility to manage risk that is seen in both the familial cancer setting and in the prenatal diagnostic setting may result in women experiencing implicit pressure to act. Women with an increased risk of ovarian and breast cancer may feel as though they have little choice but to have genetic testing and to consider risk reducing surgery, particularly if they wish to access continued care through the public health system. There is evidence that some of the women who participated in this study felt that they had to act in particular ways in order to access surgery, for example as discussed in chapter five a woman expressed concern about asking too many questions in case this was interpreted as reluctance to undergo surgery.

In considering women’s experiences of prenatal screening in New Zealand, Sarah Donovan (2010) notes that there is an assumption that medical information is valuable. Women in her study critiqued this assumption, with some women choosing not to undergo prenatal screening. These women did not view their decision as “doing nothing” or “opting out”; rather they saw themselves as choosing to take a position of “informed ignorance” and were aware that they were making a choice that was not medically or socially sanctioned (Donovan, 2010). Donovan (2010) notes that there are a consistent percentage of pregnant women in New Zealand each year who do not seek prenatal care until after the first trimester. She suggests that this may reflect a deliberate choice to avoid prenatal screening on the part of at least some women, but that the literature regarding the number of women attending for screening fails to recognise this. Instead, non-attendance or late booking is discussed as the result of insufficient information regarding options for prenatal care.

In the same way that a decision not to have prenatal screening may not be popularly accepted or medically sanctioned, the decisions of women at potentially high risk of developing cancer who choose not to have breast screening or risk reducing surgery also appear not to be medically or socially sanctioned. As with a decision not to undertake prenatal screening, these choices appear to challenge societal expectations regarding taking responsibility for one’s healthcare. While Hallowell (1999a) observed that the option of “doing nothing” about the cancer risk was seldom mentioned to clients during genetic counselling consultations, perhaps it is a facet of the terminology that is troubling for some healthcare practitioners. Rather than “doing nothing”, the option of
declining medical options for risk management could be interpreted as an individual making an active choice to decline medical management.

6.1.4 “Getting on with it” and the public health discourse

The intersection of genetics and public health is rapidly approaching. In 2009 the initial “Genes for Health” conference was held in Fremantle, Australia, bringing together researchers and clinicians from the fields of human genetics and public health. There is an increasing recognition that knowledge of an individual’s genetic background will allow people to make lifestyle modifications pertinent to their risks for particular diseases, for example, certain types of cancer and cardiovascular disease. Direct to consumer genetic testing for susceptibility to a number of different conditions including cardiovascular disease, Alzheimer disease and type 2 diabetes is now available through several publicly available websites (for example http://www.23andme.com). Given the complexities the women interviewed for this study are describing with adjusting to and managing their cancer risk, the development of appropriate services and resources for people living with genetic risk is becoming increasingly important.

The majority of the women interviewed appear to accept the dominant discourse of our larger society, the unwritten, unspoken “rules” or “expectations” about individual responsibility and agency, perhaps without conscious thought. Indeed, it may be that the reason that “getting on with it” as an approach to risk does not appear to have been reported previously in the context of genetic testing for familial cancer is because beliefs about individual responsibility are so deeply entrenched in Western society. The women in this study voice their understanding of societal expectations in comments such as the one made by a young woman with a strong family history of breast and ovarian cancer talking about options for managing her risk who says …if there’s something positive I can be doing then why wouldn’t I go there [3]. Both the women in this study and the women in Hallowell’s (1999) study repeatedly voice their responsibilities to their families, with decisions regarding risk management particularly taking into account their responsibilities as mothers and partners. The responsibilities as mothers and carers that the women in this study voice are also associated with women’s role as the unpaid care-givers in New Zealand society, suggesting that they
feel obliged to maintain their health, regardless of the cost to themselves, in order to continue to fulfil this role. This will be discussed in more detail in chapter seven.

Client autonomy and informed decision making, within which ideas regarding personal responsibility are implicit, are central facets of genetic counselling practice. They have arisen and developed during a similar time period as the moves to reduce the patriarchal and paternalistic grip on medicine. The language that predominates in genetic counselling is a language that reinforces ideas of individual autonomy, informed choice and non-directiveness, at least in some settings. The principle of non-directiveness was initially adopted in an attempt by the profession to distance itself from the eugenic movement. It has been a contentious principle for some years now, resulting in significant discussion (see for example Biesecker, 2001; Brunger & Lippman, 1995; Hodgson & Spriggs, 2005; Kessler, 1992; McConkie-Rosell & Sullivan, 1999; Michie et al, 1997) and an understanding that the value neutrality the principle implies is impossible in practice and is not appropriate to all genetic counselling situations.

Koch and Svendsen (2005) suggest that genetic counselling is now situated in a medical setting that promotes health. They argue that attending genetic counselling to acquire knowledge about one’s personal risk is the first step in cancer prevention for at-risk individuals. The idea that individuals attend genetic counselling to clarify their personal risk of developing cancer is reflected in the stories of the women interviewed for this study and described in the previous chapter. Biesecker (2001) suggests that the goal of genetic counselling in familial cancer clinics is similar to the goal of other health education programmes, in that the client develops an understanding of their disease risk and their options for health-promoting behaviours. The acquisition of information about cancer risk theoretically results in autonomous decisions regarding risk reduction and is viewed as an exercise in responsibility, both personal responsibility for one’s own health and familial responsibility as the information will also be useful for one’s genetic relatives (Koch & Svendsen, 2005). Most of the women in this study appear to be comfortable with the acquisition of risk information and with using this information to make decisions that will allow them to “get on with” their lives. For a few women, the situation is more complex in that they appear to be willing to seek information regarding their risk and to understand the discourse around using the information to “get on with” their lives, but actually putting this into practice is more difficult for them.
6.2 Struggling to “get on with it”

There are a small number of women whose interviews do not have the matter of fact tone I have described above. These women often speak in ways that are difficult to listen to, and it is in these interviews that tears rather than laughter occur. These women describe their struggle with the knowledge of their increased risk in such a way as to make one suspect that the fear and anxiety permeates their daily lives. When asked about how she feels about the increased risk of developing cancer, one woman says it sits there, it sits there… [8] and another woman says yeah, so it’s there all the time [31]. Some of these women make comments that could be interpreted as being matter of fact, but that are often contradicted by the preceding or following comments. For example one young woman who was very distressed in the months after receiving a positive BRCA1 predictive test result says I do feel very lucky to have that knowledge. It does feel heavy sometimes [13]. These women are describing a pervasive sense of unease about their risk that is sitting with them in their daily lives.

Meiser (2005) reviewed the literature regarding the impact of genetic testing for hereditary cancer susceptibility and found that the results of studies assessing psychological distress after a positive BRCA predictive test in unaffected women are inconsistent. Most studies using formal measurements of anxiety and worry in this review report no significant changes in psychological outcome after a positive test result relative to baseline. However, an Australian interview-based study suggested that there may be a period of initial emotional turmoil after receiving the results (Lim et al, 2004) and some of the women interviewed for the current study also described a period of distress after receiving their result. This woman described the intense emotions associated with receiving her result, followed by several months of distress:

I went up and she told me and spent about an hour with me and then I basically went to the toilets in the [Name] Hospital and had a cry. I went up by myself which was very silly. She did suggest bringing someone, I didn’t really think about it… it hit really hard. It was hard. It hit really hard actually. Yeah I spent a few hours, I sat in the toilet and cried… I think I kind of spiralled down really and maybe I became depressed I don’t really know but I certainly
wasn’t myself. I had, (pause) I had an interesting six months really
[13].

In a recent review of the literature regarding survivorship considerations in BRCA mutation carriers, Croster and Boehmke (2009) report that, of eighteen studies measuring cancer related distress after genetic testing, only three found increased distress. As with studies of anxiety and worry, they report that when distress is present, it is not usually clinically significant.

While studies using psychological measures may not find measurably increased levels of anxiety and distress, qualitative, interview-based studies provide an alternative way to understand the distress that may occur as a result of receiving a positive genetic test result. The use of comparative analysis during the data interpretation encouraged consideration of the differences between the group of women who were “getting on with it” with those who appeared to find this more difficult. As previously noted, it is the overall tone and feeling of each interview that suggests a woman’s approach. Comments made by the women whose interviews suggest difficulty “getting on with it” indicate that they have an implicit understanding of what is expected within New Zealand society, the expectation that, when faced with a challenging or difficult situation, individuals will “get on with it”. One young woman, who carries a BRCA1 mutation, describes periods of anxiety and talks about how she has been meaning to arrange surveillance in the town where she is currently living. She makes the comment about being lucky to know about her mutation status but feeling the weight of this knowledge. Her interview indicates very real difficulty in planning her health care and she is undecided about management options. She reports a conversation about risk reducing oophorectomy with another woman who also carries a BRCA mutation in which she recalls saying that you just do what you have to do [13]. This comment suggests that she understands the societal discourse around “getting on with it” and can apply this concept in a social situation, but her interview indicates that she has more difficulty in applying the concept to her own situation. She goes on to say

... no matter how bad it is, it’s gotta be better than being dead.
That’s my, that’s what I think. What are your choices? You don’t have lots really I don’t think [13].
The women interviewed for this study appear to be aware of societal, cultural and
gendered expectations regarding living with risk. However, not all of the women are
able to mobilise themselves to act in ways which reflect these expectations. A small
group of women indicate that they know what is “expected”, but that actually putting
that into practice is difficult for them.

The differences between the two groups of women are evident not just in the tone of the
interview, language that is used and the scarcity of matter of fact comments; these
women appear to behave differently and to think about themselves and the health
practitioners they encounter in a different way. Health practitioners are described as
“they”, as being in some way other, disconnected from the woman, rather than being a
person with whom they can have a meaningful interaction. One woman describes her
health care as being up to them, up to them [5] and another mentions that she left it with
[Genetic Counsellor]… I don’t know where it’s going [31]. These women talk in ways
that suggest they view their health care as being in the hands of medical professionals. 
One of these women described feeling pretty powerless [31] and went on to say:

I just feel that I’m not a priority because I’m not showing
symptoms or because I’m in a certain age bracket, that yeah
they’re not going to think seriously about it at all really. [31].

During the interviews, the interviewer urged several of these women to re-contact the
 genetic service to clarify the matters that were concerning them. None of these women
re-contacted the genetic service after their interview.

There are deeply entrenched power differentials between health practitioners,
particularly doctors, and “patients”. These are gradually being challenged as “patients”
demand more information and the right to make their own decisions about their health
care. The women in the group who are “getting on with it” talk about their medical
specialists in ways that suggest they have an interactive relationship, that they regard
themselves as partners in seeking information and making decisions. They are more
likely to use their doctor’s names than to refer to their doctors as “they”. Both their
language and behaviour suggest that they have embraced the messages about rights and
autonomy in health care and feel comfortable with this more equal relationship. In
comparison, there is a small group of women who do not describe that sense of
partnership with their health care providers.
The interviews with this small group of women also reveal limited knowledge of the way in which their bodies work in comparison with most of the women who participated in the study. One thirty-four year old woman talks about how she had heard that lots of women had hysterectomies and did not think this was going to be a problem for her. Recently she learnt that having her ovaries removed would mean that she would experience menopause, saying *I honestly had no idea about menopause* [13]. As previously mentioned, a woman in her late fifties and postmenopausal, talking about how she might manage her risk of developing ovarian cancer says

* I guess if I have my ovaries out I’m obviously on some form of hormonal thing to keep me from becoming a man.* [32].

This woman is the only postmenopausal women for whom risk reducing salpingo-oophorectomy was indicated who has not had a salpingo-oophorectomy. Her comment is almost identical to one used by British researcher Nina Hallowell in the title of her 1998 paper looking at women’s perceptions of prophylactic surgery as a risk management option, where a respondent said to her “You don’t want to lose your ovaries because you think “I might become a man””. As a practicing genetic counsellor, I have experience with women making comments that reveal limited understanding of ovarian function. For example I have occasionally been asked by postmenopausal women if having their ovaries removed would make them more like a man. These comments suggest that some women have limited knowledge of what happens either with the natural cessation of ovarian function or with surgical removal. These women may in fact be asking about the physical changes that accompany menopause, with the possibility of changes in body shape, hair growth and other changes which may be regarded as less feminine. Regardless of this, the question, when asked by a woman who is postmenopausal is suggestive of limited understanding of ovarian function.

Other researchers have also been reminded of the varying degrees of knowledge that women have about the workings of their bodies. In her thesis exploring New Zealand women’s experiences of hysterectomy, Glenys Barker (1999) found that she was constantly reminded that the women she was interviewing had little knowledge about the facts around menstruation and menopause during the interviews. Gail Darke (1996) interviewed women about their experiences of menopause and found that these women’s knowledge about the way in which their body worked and the effect of a
medical intervention such as a hysterectomy was partial. A number of the women interviewed by Hallowell et al (2004) reported experiencing significant anxiety and distress after their surgery because they had not been aware of the physical and emotional sequelae of a surgical menopause. All the women in her study would have liked to receive more information about the range of menopausal symptoms and the use of hormone replacement therapy prior to undergoing surgery. In a study examining the psychological impact of risk reducing salpingo-oophorectomy, the women also reported wanting more information about the physical effects of the surgery and said that they felt emotionally unsupported after the surgery (Meiser et al, 2000).

The indications from the women interviewed for this study are that some women, particularly those who are “getting on with it”, will seek the knowledge they require to make decisions both from their health care providers and from other sources such as the internet. However, as described in the previous chapter, some information may be hard to come by even for very motivated women. Most of the women reported receiving little or no information about the impact on body image and sexuality of risk reducing surgery. For a small group of women, access to adequate information and education appears to be difficult, and consequently they may not receive appropriate risk management even though they sought this when they attended the genetic clinic initially. As familial cancer services develop and become integrated with public health services and dialogues, it will become increasingly important to identify the barriers that are currently limiting access to information and services. It may be that additional funding is required so that services are able to offer more than one appointment, allowing women to make return visits as they absorb complex information. In a presentation exploring the association between genetics and public health, Andrew Faucett (2010) noted that most people can absorb three new pieces of information in one consultation or educational event. This suggests that most people are likely to need several interactions with genetic counsellors and medical practitioners to fully understand the information associated with carrying a familial cancer predisposition.
6.2.1 Access to medical services for women who struggle to “get on with it”

You know it’s not until I actually get dragged in on a trolley that they’re really going to sort of...

AG: So you feel a bit neglected really?

Yes I do actually. Yes [31].

Accessing medical services seems to be particularly daunting for a small number of women in this study. They indicate that they want to have surveillance but report feeling powerless and describe appointments with surgeons as nerve-wracking. Difficulties in access and a sense of reluctance to seek medical services by these women is perhaps not surprising when one considers the long history of patriarchal dominance of the medical profession and particularly of women’s reproductive capacities. While there are now many more women practicing medicine, the interaction between a medical “professional” and a “patient” still suggests a power differential in which the “patient” is assumed to have less knowledge and therefore less power than the “professional”. It is unsurprising that some women struggle to obtain adequate information when one considers that the interaction with the health practitioner begins with the assumption that the health practitioner has knowledge and the woman does not.

Dorothy Broom (1995) suggests that medicine is masculine in ideology and gendered in practice, with a masculine style of interaction continuing despite increasing numbers of female medical professionals. It is only as a result of movements such as the Women’s Liberation Movement, starting in the early 1970s, that women have begun to reclaim their bodies from the medical profession with moves to regain control over women’s reproductive capacities and increase understanding about experiences such as menstruation and menopause (Dann, 1985). The emergence of the field of bioethics and the influence of medical consumerism were also important in questioning long-standing paternalistic medical practices (Manning, 2009). In New Zealand, the Cartwright Inquiry in the late 1980s exposed the actions of Dr Herbert Green in conducting experimental medicine on women with cervical changes without their knowledge. The repercussions of one doctor’s actions have reverberated through the health system in New Zealand, resulting in sweeping changes to the law and the development of
practices regarding health consumer’s rights and informed consent (Manning, 2009; Skegg, 2009).

The shift away from the “doctor knows best” approach to medical consultations is taking place gradually. While the women’s movement encouraged a generation of women to learn more about the natural workings of their bodies and the Cartwright Inquiry resulted in further changes to the New Zealand health system, it is clear that these events have not reached every individual. The participants in this study describe a range of styles of interaction with their doctors and report widely varying interactions with health practitioners, with some women able to successfully negotiate the “system” to get the information, support and services they require, while other women are left feeling neglected, powerless and let down.

6.2.2 “Getting on with it”: societal and cultural influences

The women interviewed for this study appear to understand that “getting on with it” is a dominant discourse in New Zealand society and that therefore the expectation is that they will “get on with” managing their cancer risk. While Darke, (1996) suggested that “getting on with it” may be a gendered expectation, I would like to suggest that it is in fact not solely a gendered expectation. The few studies that have noted women “getting on with it” are all British studies. New Zealand has significant historical cultural links with the United Kingdom and the women interviewed for this study are all of “European” ancestry. “Getting on with it” in the context of this study may therefore have both gendered and cultural expectations. The following exert indicates that some women may be aware that cultural discourses have a role in their approach to risk:

*We have talked about what they do in America, you know find out from the early the younger women and how they have everything removed.*

*AG: They do. I’m startled to read some of those stories.*

*And I’m going oh why don’t you just get tested, you know. This is so drastic. And surely really good testing for that cost of all the surgery, put that money into constant testing if that will make you feel better. But I mean imagine if I’d been like that and nothing’s happened to me*
and I’d gone through hell as a really young woman and I mean okay everyone’s different, but they’re a bit too over the top I think. It’s not the Kiwi way.

AG: No it’s not the Kiwi way. I’ve been struck by that.

Yes I mean I think quite, we do what’s sensible but we try not to go over the top. [14].

This excerpt of an interview with a sixty year old woman who carries a BRCA2 mutation and who has a sister and nieces who have lived in America for many years identifies the perception that the way New Zealanders approach things is different from the way in which women in America approach their risk. In addition to having family in America, she has spent a lot of time on the internet and notes differences in approach resulting in her comment about women in America being a bit over the top. In particular, she suggests that the Kiwi way is to be sensible.

The way that New Zealand women approach their risk is likely to be influenced by cultural and societal influences that are unique to New Zealand. There are many components that may contribute including elements of our national identity and the shared history of New Zealand, elements of gender identity, aspects of New Zealand history and social and governmental policy that have contributed to the formation of gender identities in New Zealand, and the increasing expectations around personal responsibility at both a national and international level. The strength of the finding that New Zealand women are “getting on with it” may therefore be attributable to a combination of gender, cultural and societal expectations associated with being a New Zealander.

As noted above, almost all of the women make comments indicating an implicit awareness of sets of understandings within society that encourage them to behave in a particular way about their risk. This observation suggests that taking personal responsibility, in this case for one’s health and well-being, is a dominant discourse in our society. The ability to take responsibility for our own health is viewed positively in today’s society, both within New Zealand and in Western societies more generally. Alan Petersen (1999) has suggested that, in order to understand what occurs in genetic counselling, an appreciation of the dominant, neo-liberal mode of governance is
necessary. Neo-liberal governance places emphasis on local and individual autonomy, providing governance from a distance, with the goal of “creating” individuals who operate autonomously (Petersen, 1999). Individuals are expected to govern themselves, and this includes managing their own risk (Petersen, 1998). In New Zealand, neo-liberal government policy was established in the 1980s and has included policies aimed at fostering self-reliance and personal choice in matters such as health care and education (Kelsey, 1997). Neo-liberal policies in public health result in imperatives about health promotion and, again, are associated with efforts to persuade individuals to take greater responsibility for their own health (Petersen, 1999). Public health messages exhort individuals to take responsibility for maintaining a healthy lifestyle, to avoid risks, to participate in publicly funded screening programmes and parents are encouraged to have their children immunised for a number of diseases. While these messages predominate in New Zealand society, there is evidence from some of the women in this study of the difficulty in accessing and utilising services, with women reporting that they feel that I’m not a priority [31] and that they see from the letter it should have been followed up, anyway it wasn’t [23]. In a health system that places responsibility on individuals to initiate follow up, the chance that some people will be lost to follow up and will have difficulty finding their way back into “the system” is significant.

It is reassuring that the majority of women interviewed for this study are clearly indicating that they are not letting the increased risk of cancer stop them from getting on with their lives. Genetic counsellors can perhaps learn from the women in this study who struggle with the increased risk – the women who are less able to “get on with it”. It is important that genetic counsellors attempt to identify those women who are likely to struggle while they are in the genetic clinic. They can then ensure that these women have regular follow up for some time after their appointments. In this study, these women are identifiable by indications that they are more passive in regard to health care, by indicators of distress such as tears, and by a more limited understanding of the ways in which their bodies work, particularly with regard to ovarian function. These factors may be identifiable in the genetic counselling appointment, although more work will be required to confirm this.
6.3 Ways of approaching risk “run in families”

There is some evidence in the interviews to suggest that the way of approaching one’s cancer risk runs in families. The women draw on the approaches of former generations and in particular of their mothers. A woman who has had bilateral breast cancer, makes several comments about how she is not going to make it my life and does not live daily worrying I would get it [1]. Towards the end of her interview she talks about her mother, saying she was probably a pragmatic person, she just got on with things [1]. Another young woman who carries a BRCA1 mutation and has had a risk reducing mastectomy says I’m like Mum like that, matter of fact [19]. The women in the study also talk about drawing on their relative’s experiences and taking strength and encouragement from them, for example one young woman talks about her mother’s experiences with sequential cancer diagnoses and says ... if she can do it you know it can give me strength to do things like that [3].

In the same way that some of the women draw strength and an attitude of “getting on with it” from other relatives, particularly their mothers, the interviews with women who do not take this approach to life also indicate the familial nature of different approaches. One woman, whose mother did not seek medical attention for symptoms of cancer until the disease was well-progressed, says

\[
I \text{ think when your time’s up, it’s up… Yep, everybody’s got to die. And not everybody’s going to live to old age...} [5].
\]

Another woman comments that my Mum and Dad chose to protect us from it and goes on to say

...when she died it was a real shock for us because even though we knew that she was sick and she went into the Hospice death was never talked about and then when it did happen it was like you know wow. Yeah it was a real shock to me… [31].

Families pass traditions, cultural expectations and behaviours, and social structures through the generations, within the context of prevailing societal discourses. This may include expectations to behave in certain ways. The comments of some of the women interviewed for this study suggest that the way that they approach their risk is influenced by familial expectations and behaviours. Werner-Lin (2007) uses Bowen’s
family systems theory to suggest that beliefs and patterns of coping and adaptation are passed down through the generations of families with hereditary breast and ovarian cancer. While her study focused on the family stories about the types of family members who get sick and the ages the illness occurs, the women in the present study appear to be using family patterns of behaviour to identify and support ways of approaching their risk. This is not surprising given the evidence indicating that risk perception is influenced by an individual’s experiences of cancer in their family as well as by the risk figures that they are given. Dagan and Goldblatt (2009) also found evidence that the mother’s story shapes their daughter’s experiences. They suggest that the way that mothers coped with their own diagnosis of cancer and subsequent illness and death influences the way that their daughters cope with knowledge of their own increased chance of developing cancer.

6.4 Other factors influencing ways of approaching risk

A number of other themes emerged from the interviews that appear to influence the ways in which these women approach their increased cancer risk. These include worrying, and choosing not to worry, fatalism and a feeling of inevitability, fear, determination to fight, and a feeling of safety associated with the belief that carrying a cancer predisposition mutation will facilitate monitoring and surveillance. These themes were seen across both groups of women. The differences lie in whether or not an individual uses her fear or worry to motivate her to attend for surveillance or to consider risk reducing surgery. Some women appear to be able to use their anxiety to mobilise their determination to do all they can to reduce their risk, while other women find the worry and fear overwhelm them in a way that makes action difficult, or in a few instances, impossible. This section comments on each of these themes and considers their influence, if any, on “getting on with it”.
6.4.1 Worrying and choosing not to worry

Tell me the worst and then tell me it’s not going to happen [4].

In today’s society, women are often seen as being responsible for the health and wellbeing of their families, their partners and children, to the extent that one young man interviewed as part of a project exploring gender difference in health talk stated that “men are leavers alone and women are worriers” (Charles and Walters, 2008, p.128). What happens then, when it is the woman, the mother, who has the health concern? Does she continue to take responsibility for the health of her family as well as managing her own health concern? Does she worry?

It is clear from the responses of the women interviewed for this study that they do worry. They identified both general and specific worries in regard to the increased risk of developing breast and ovarian cancer. A number of the women mentioned concerns that appeared to pervade their daily lives, for example:

There wouldn’t be a day that goes by that I don’t think about it… [9].

But it’s there. It’s there [18].

So it still is there in the back of my mind [20].

These comments, and others like them, suggest that for some women the increased risk of cancer is an ongoing concern that accompanies them through their daily lives. Societal constructions of gender and the view that worrying about one’s health and engaging in health promoting behaviours are “women’s business” (Charles and Walters, 2008; Coward 1992; Pandey et al, 2003) may contribute to the underlying explanation for the pervasive worries about cancer development these women are expressing. That aside, these women are carrying a considerable burden of worry on a daily basis.

Worries about their children and grandchildren are mentioned by a number of women, for example one woman who was in her late fifties when she had predictive testing for a familial BRCA2 mutation says I’m more worried for my son who’s got the three daughters [14] and another woman says I’m worried about my daughter [1]. Women also worry about the impact that their own risk has on other family members. This feeling is described well by a young woman with a maternally inherited BRCA mutation, who
had had a bilateral risk reducing mastectomy and was planning a risk reducing salpingooophorectomy. She says *I think it’s been harder on Mum than it has been on me, yep* [19]. She is articulating the belief that it is sometimes harder for other family members to watch a loved one live with the increased cancer risk than it is for the person with the mutation.

Decisions regarding genetic testing have been shown to be influenced by a feeling of responsibility towards others, including partners, parents, siblings and children (D’Agincourt-Canning, 2006). The knowledge of the fact that other family members are worrying has been shown to influence a woman’s decision making (Rowley, 2007). These reports and the findings of the present study indicate that worry is influential both by the effect of one’s own worry and as a result of feeling as though others are worrying about one, and acting to try and alleviate those worries.

Women identified worries related to risk reducing surgery, including worries about body image after risk reducing mastectomy and concerns about the effect of a surgical menopause on their personality and the possible effects this will have on their partner and family. One women talks about worrying that surgical menopause will turn her into a monster, but like other women, she justifies the decision to proceed with surgery by the belief that her partner and children would rather have her alive and with them than not. Again, the importance of family and the feeling of being needed by the family are made overt in influencing decision making.

Medical appointments are a specific cause of worry with women describing appointments with surgeons as *incredibly nerve-wracking* [16] and *intimidating* [29] and talking about their anxiety in the days leading up to an appointment for surveillance or follow up. They justify the decision to have risk reducing surgery with comments such as *I didn’t want to live with that anxiety* [16], suggesting that one of the motivations for surgery is to reduce their own worry. As previously discussed, a number of studies have found that women undergoing risk reducing surgery report a reduction in anxiety and a feeling of freedom from cancer-related fears (Meiser et al, 2000; Babb et al, 2002; Lloyd et al, 2000; Kenen et al, 2007).

Women approach the matter of whether or not to worry about the increased risk in different ways. Some women make comments that suggest that they make an active choice not to worry about this risk, saying *I won’t go thinking about it all the time, no*
...you try not to concentrate on it [22]. While the current study did not attempt to explore the specific ways in which women may manage their worries, Crouch and McKenzie (2000) considered this when interviewing women who had had a mastectomy after a breast cancer diagnosis. They found that some women developed lifestyle behaviours and daily routines as a means to control their fear of a recurrence of breast cancer. While some women appear to be able to use their concern to motivate decisions regarding managing their risk, this is not the case for all women. It is possible that these women incorporate other means of controlling their worry into their daily lives. This may be an area for further research, particularly as the potential to identify individuals at increased risk of a number of common health conditions develops.

...I mean felt like a ticking time bomb really. I just thought you know why wait? I want to be proactive rather than wait... [19].

There does not appear to be a direct association between the women who take the approach of “getting on with it” and expressing less worry. Women in the group who are “getting on with it”, such as the woman quoted above, talk about their worries in much the same way as women who appear less able to “get on with it”. However, many of the women in the group who are “getting on with it” are making surgical decisions which may ultimately result in less worry about the chance of developing cancer and an increased ability to, as one woman puts it, move on.

6.4.2 Fear

...secret fear that I might get ovarian cancer [12].

It is scary... I was really scared [17].

...find a lump or something I freak out [3].

A number of women described their fears during the course of the interviews. These fears included fear experienced at the time of a cancer diagnosis, fear of developing ovarian cancer, fear of being judged for choosing to have risk reducing surgery, and the fear of one day finding a breast lump. Women who had had a previous diagnosis of cancer talked about the fear they had experienced around the time of their diagnosis describing feeling totally totally terrified [7] and saying I did feel really scared at first.
A number of women talked about having a general view of cancer that is something scary or that rings alarm bells [3].

Some of the women expressed specific fears, for example women talked about being particularly fearful of getting ovarian cancer, which is understandable given that ovarian cancer often presents at an advanced stage with very non-specific early symptoms. The very real fear of developing ovarian cancer has been reported in earlier studies, with women in Babb et al’s (2002) study expressing a desire for their doctors, family and friends to understand how powerful this fear was for them. One of the women who had chosen to have a risk reducing mastectomy talked about her fear of being judged [16] for the decision to proceed with surgery. She chose not to tell very many people about the surgery and described the resulting isolation as being very difficult.

Every time I have a shower I fear and sometimes you know have a really good quick wash and don’t like feeling [15].

This woman aptly described the way that fear permeates daily life to the extent that she fears finding a breast lump when she showers. Another woman talked about the fear that this thing could get me [9] that arose from the genetic counselling appointment at which she was offered BRCA mutation analysis.

The expression of cancer-related fears was common across both the group of women who are “getting on with it” and the women who are less able to “get on with it”. As with worrying, the women who are “getting on with it” are more likely to take actions to try and reduce their fears, for example attending regularly for surveillance or choosing risk reducing surgery.

6.4.3 Fatalism and a sense of inevitability

You’re going to die of something aren’t you? [1].

… if I get it I get it, if I don’t I don’t… [5].

… if it’s going to happen, it’s going to happen I suppose… [23].

… expectation that one day I would get cancer [24].
Some of the women make comments that suggest that they see a diagnosis of cancer as inevitable. While some of the women take active steps to reduce the chance of a cancer diagnosis, others appear to wait and see what happens. The woman quoted above as saying that she has lived with the expectation that she would get cancer has responded to receiving a positive BRCA1 predictive test result by having a risk reducing bilateral mastectomy and a salpingo-oophorectomy, actions which will substantially reduce the possibility of a cancer diagnosis associated with carrying a BRCA mutation. Along with adjusting to the results of the surgery, she is adjusting to a different future, one in which a cancer diagnosis is now no more likely than for other women in the general population.

Other women take a less proactive approach in medical terms, with some appearing to prefer to leave their future to “fate”. Several women mention not being sent clinic appointments for screening, or being unsure about what is meant to happen with their follow up. A few women also mention having forms for blood tests and mammograms but not having arranged the tests.

\textit{AG: And so what have you been doing?}

\textit{Nothing yet. I’ve got the bit of paper on my fridge up there to make an appointment for the scan and ultrasound [31].}

One response to risk is to do nothing about it, to take a fatalistic or passive approach (Alaszewski & Coxon, 2008). This approach has been associated with situations in which the risk seems overwhelming (Alaszewski & Coxon, 2008), which may be the case for some people facing a genetic risk of developing cancer. The risk is internal, carried in each cell in their bodies, a fact which may contribute to the feelings of helplessness or inevitability some women describe. Ulrich Beck (1992) notes that, in the face of hazards or dangers, humans “become active today in order to prevent, alleviate or take precautions against the problems and crises of tomorrow and the day after tomorrow – or not to do so” (p. 34). As can be seen in this study, some women with a BRCA mutation become active to prevent, or at least reduce the risk of a diagnosis of cancer. Note that Beck comments “or not to do so” indicating that some people may not take action to try and prevent or alleviate certain risks. In the same way, some women in this study have not yet, and may never, become active to reduce their risk using medical management. Where “there is no escape, people ultimately no longer want to think
about the hazard or risk (Beck, 1992, p. 37). While Beck is discussing overwhelming, global environmental risks, the same could be seen to apply to an intrinsic, internal risk like a BRCA mutation. “Doing nothing” may in fact be an effective way of dealing with certain types of risk, although it may seem non-rational to outsiders (Alaszewski & Coxon, 2008). Koch and Svendsen (2005, p. 826) suggest that genetic counselling for familial cancer is now situated in a health promoting medical setting and that, if cancer genetic counselling is seen as a social technology, then it “specifically concerns the shaping of behaviour to further the choice of a healthy life”.

As a practicing genetic counsellor, conducting this research has been confronting, illuminating assumptions which were so entrenched as to be unquestioned. Training in genetic counselling emphasises individual autonomy for clients and considers the ways in which truly informed consent can be facilitated. As noted above, choosing not to pursue genetic testing, choosing not to have surveillance and choosing not to have risk reducing surgery may be viewed as effective or reasonable choices by some women attending a genetic clinic. Yet Hallowell (1999a) has observed that the choice not to have a medical intervention is not always provided to clients and, if Koch and Svendsen’s (2005) argument stands, genetic counsellor’s are in the business of promoting health, and by extension promoting action by way of surgery or surveillance for these women. Informal discussions among genetic practitioners also suggest that choosing not to use medical options to reduce risk is viewed as unreasonable and illogical, despite much discussion regarding client autonomy and informed choice. If genetic practitioners are going to promote truly informed choice, there must be an acceptance that, for some individuals, choosing not to act on the medical information about their risk is a viable and reasonable alternative.

6.4.4 Determination and fighting

While the women talked about the things that worried or frightened them in relation to cancer, many of them were also explicit in their determination to do all that they could to avoid a cancer diagnosis or to avoid the same fate as family members who had died of cancer at an early age. Many of the women who have had surgery talk very clearly about their reasons for making the decisions they have made, for example:
… well I’m not going to go that way [24].

We both know its major surgery but you just have to do it [27].

…there’s no way I’m going to let them grow up without a mother [29].

There was no way I was going there [30].

These women are all part of the group of women who also talk about “getting on with it”. All the women quoted above have chosen to have risk reducing surgery, indicating that they are prepared to take practical medical steps to reduce their risk and to “get on with” their lives. Attributes of femininity are drawn from societal assumptions and expectations about behaviours and characteristics associated with people of each gender. Characteristics such as strength and decisiveness are traditionally associated with masculinity, with the assumption being that feminine characteristics are “the opposite” (DeFrancisco & Palczewski, 2007). Many of the women interviewed for this study demonstrate strength, decisiveness and resilience, as illustrated by the comments above.

In New Zealand we have perhaps challenged some of the gender norms of Western society. In the introduction to their book on feminist scholarship in New Zealand, Weatherall, Potts and Gavey (2004) suggest that this scholarship emerges from a societal, political and cultural context that has often lead the world in challenging thinking about gender. New Zealand has a strong history of emancipation for women, recognising that women’s views deserved recognition in the governance of our country by becoming the first country to give the vote to women, in 1893. More recently, New Zealanders have elected two female prime ministers and women have held a number of other senior positions, including those of Governor General, Attorney General and Chief Justice. Public dialogue on websites such as Wikipedia suggests that New Zealand women may choose to dress in ways that are less feminine and more practical for our environment than our overseas counterparts. There is an expectation that New Zealand women will be resourceful and self sufficient, an expectation that may have grown out of our history as a settler society in an environment where a certain toughness and willingness to work was required and where women were initially significantly outnumbered by men and lived in a more masculine environment (Adam, 1874; Levesque, 1986). Strength and decisiveness among both women and men was
required in the pioneering days of New Zealand settlement and, based on the comments of the women interviewed for this study, continues to be a part of New Zealand society for many women today.

The transcripts of a small group of women are not permeated with the same sense of determination to confront their cancer risk in ways that are expected by the medical profession. These are the same women who have difficulty “getting on with it”. The majority of this group of women had not had risk reducing surgery at the time of their interview and several of them commented that they had not followed up on overdue appointments for surveillance. These women are perhaps behaving in ways that suggest more traditionally feminine characteristics such as weakness and dependency as described by DeFrancisco and Palczewski (2007). However, as noted above, choosing not to act on their risk may be a way of dealing with uncertainty for some people, rather than a specifically feminine characteristic. These women may be taking a more holistic approach to their health, which this study did not investigate. These characteristics appear to differ from the majority of the women in this study, and overall the findings of this study indicate that some New Zealand women may be challenging traditional Western norms of femininity.

6.4.5 Feeling safe

One of my sisters said to me, my one sister who had a negative result said to me, I couldn’t believe she said. She said, oh she’s a bit of a hypochondriac this sister, she said oh you’re the lucky one. (laughter) She did. And I was pretty gob smacked and I thought well what does she mean? Well actually what she means is I’m the lucky one because I’m going to be the one that will be followed and checked and a close eye will be kept on me. Whereas plenty of people do get breast cancer and it’s got nothing to do with them having any sort of gene, yep. So I’m the lucky one because I know and there will be all sorts of people looking out for me [4].

A number of women appear to find reassurance in the knowledge that they carry a cancer predisposition mutation as they believe they will receive better care than people
in the general population. The woman quoted above is one of five sisters, two of whom carry a BRCA1 mutation. Her sister was also interviewed and expresses a similar viewpoint when she says

*Well it makes you more interesting to the medical profession I’m sure. They take you seriously* [1].

Other women comment that access to regular monitoring makes them feel *reasonably safe* [28] and *really lucky* [13] because surveillance *gives me sort of reassurance* [12]. For one woman in the study, the knowledge that she carried a BRCA2 mutation and the decision to have a risk reducing salpingo-oophorectomy probably saved her life when an occult fallopian tube cancer was diagnosed after the surgery. She acknowledges this during the interview and says that knowing about the mutation and being able to access risk reducing surgery is *just wonderful* [7].

In the risk society described by Beck (1992), safety becomes a motivating force. It appears that for many of the women facing an increased risk of cancer interviewed for this study, safety from that risk has become a motivating force. They construct a feeling of safety out of a sense of being “interesting to” and therefore somehow protected by the medical profession when attending for screening, or a feeling of safety as a result of risk reducing surgery. Other studies have also noted that a feeling of safety is associated with knowledge of genetic status for a few women. D’Agincourt-Canning (2006) found that receiving a genetic test result lead to a change in self-perception from an uncertain self to a safer self for a few of the women in her study. Kenen et al (2003) noted that a few women in an interview-based study of women from hereditary breast and ovarian cancer families made the connection between carrying a cancer predisposition mutation and receiving better health care. Kenen et al (2003) used the notion of heuristics (inferential shortcuts which are used to help make sense of complex information) to explore the way that the women in their study made sense of the genetic information they received. They suggest that making the connection between carrying a mutation and receiving better care is associated with an illusion of control heuristic. In situations where there is a significant level of fear and where control is important, people may persuade themselves that they can exert a high level of control over potential outcomes. The identification of a feeling of safety and of being more *interesting* and taken *seriously* by their doctors deserves consideration in relation to earlier discussion
regarding the inherent power differential in interactions with medical professionals. As noted, there is an inherent assumption that medical professionals have more knowledge and “patients” have less knowledge. The comments of these women suggest a felt need to capture the attention of the medical professional in some way that makes them memorable in order to receive appropriate care.

As previously discussed, a number of the women in the current study identified areas in which they had, or were planning to, exert control over their risk by having risk reducing surgery. The view that carrying a BRCA mutation makes one more interesting to the medical profession and results in women feeling reasonably safe is associated with the general desire to “get on with” their lives expressed by many of the women in this study.

6.5 Conclusion

The women interviewed for this study identified a number of different ways of approaching their risk, including feelings of determination, inevitability, fear, and worry, along with feelings of safety induced by regular surveillance and being viewed as interesting by their doctors. These attitudes have previously been reported in other interview studies of women who carry BRCA mutations or are at increased risk of breast and ovarian cancer based on their family history in a number of Western countries.

A very strong desire to “get on with it” is expressed by these Pakeha New Zealand women. Attitudes or ways of approaching risk are likely to be strongly influenced by the period in which people are living, the political discourses that are predominant at the time and by societal ideas around national identity, in this case around how Pakeha New Zealand women think as a people. Extrapolating that idea out to suggest that, as a people, New Zealanders tend to “get on with it” resonates with many people. It is present in our media and reinforced as part of our national psyche by the political and societal discourses that predominate.

As a society we are asking questions and discussing issues such as the right to health care for all and the place of individual responsibility in accessing health care. Increasing options for surveillance aimed at early detection of cancer are altering the way that we
think about health and at the same time altering the role of health practitioners, requiring them to persuade individuals to take responsibility for managing their own health risks (Hallowell, 1999). This broad shift in governance is reflected in the emphasis on autonomy, empowerment, informed choice, the right to know and non-directiveness in genetic counselling (Petersen, 1999). The shift towards self governance and personal responsibility for managing risk can be seen in public discourses including public health messages about weight management and smoking cessation for example. New Zealand women who have an increased risk of developing ovarian and breast cancer live in a society where neo-liberal policies have been systematically applied for over twenty years. A number of the women in this study are now aged in their late thirties and early forties, and have lived with these policies and the resulting messages about self-responsibility for their entire adult lives. That they may feel pressured at some level by societal expectations to use medical interventions to take responsibility for managing their risk is understandable because this model is dominant. In the case of hereditary breast and ovarian cancer, taking responsibility may mean agreeing to risk reducing surgery.

The women in this study frequently reference family reasons for pursuing genetic testing and making surgical decisions to manage their risk. They identify as mothers, partners, siblings, daughters, friends, women, New Zealanders. They identify a sense of personal responsibility to medically manage their risk so that they can continue with their other responsibilities. Many of the women strongly identify with their role as mothers, in particular, and with the responsibility that they have to remain alive and well to care for their children. Throughout the research conducted by Nina Hallowell among at risk women in the United Kingdom, there is a strong thread of discussion regarding the responsibility that the women she interviewed felt for their families, their partners and children, which is echoed by the New Zealand women interviewed for this study.

Approaches to managing risk are influenced by societal and cultural messages as well as by an individual’s perception of the risk. The majority of New Zealand women interviewed for this study approach their risk with a clear desire to “get on with” their lives. I suggest that this desire is influenced by the women’s identity as New Zealand women, with our history as a settler society, our particular perspective on gender identity, and with our recent history of neo-liberalism at governmental level
contributing to a felt sense of personal responsibility for managing one’s own risk within the context of a dominant medical model.

In the case of hereditary breast and ovarian cancer, “managing” risk may mean undergoing risk reducing salpingo-oophorectomy and mastectomy. As demonstrated by the words of the women in this study, many at risk Pakeha New Zealand women are prepared to manage their risk through surgery, allowing them to “get on with” the rest of their lives. The following chapters will explore the responsibility to remain well in order to mother their children and will consider the implications of undergoing these surgeries.
Chapter Seven

*I just did it for the kids.* [19]: Mothering in the context of living with an increased risk of ovarian cancer

... there’s no way these kids are going to watch me die of cancer, there’s no way I’m going to let them go through that if I have anything to do with it and there’s no way I’m going to let them grow up without a mother [29].

In this chapter I explore the complexities of mothering in the context of risk. The women interviewed for this study live with the knowledge that they have an increased likelihood of developing breast and/or ovarian cancer, and that the cancer may occur at a younger age than for women in the general population. They live their lives and mother their children within the context of this increased risk. This chapter considers women’s identity as mothers and the responsibility for care of their children that is a strongly felt part of this role. The impact of having children of different ages is considered. The influence of being a mother on decisions regarding risk reducing surgery is explored, and finally there is a discussion about telling children about the hereditary cancer risk.

From the outset of each interview the familial context within which hereditary breast and ovarian cancer occurs is very clear. Each interview starts with the family story, providing information and context about the family members, mostly women, who have had cancer. These stories and the accompanying demographic information about each woman establish her many relational roles within her extended family. The early stages of each interview also serve to establish the woman’s roles within her family, as partner or wife and mother. Twenty five of the women interviewed for this study have children, ranging in age from toddlers to adults in their late thirties. Seven women do not have children, including two who were still considering whether or not to have children at the time of their interview. Two women had been unable to have children as a result of chemotherapy treatment for breast cancer. Mothering and the role that these women
have as mothers is central to many of their discussions regarding their increased cancer risk and their decisions regarding management of the risk.

I was so upset because I hadn’t finished having kids... I love my children ... I want to be around to see my kids grow up [19].

I, it does worry me, it does bother me. I mean my children are still young. I want to grow old. And see the kids [20].

Mothering is a powerful aspect of identity, with many women defining themselves firstly as mothers rather than by either occupation or marital status (Rogers & White, 1998). Indeed, some writers have suggested that motherhood is a life-defining status for many women (Fox & Worts, 1999). Definitions of mothering share the common themes of nurturing and caring for dependent children, involving socially constructed tasks and relationships (Arendell, 2000; Forcey, 1994). Arendell (2000) suggests that mothering has been a primary source of identity for most women since the 19th century, with the historical development of a woman’s place within the family being to bear and nurture the children and care for her husband. In the past, a woman’s worth was based on her fertility and on her attractiveness to men (Holland & Adkins, 1996). Holland and Adkins (1996) discuss forms of social control around women’s bodies and note that many of these activities are centred on a woman’s womb, on her reproductive capacity. They pose the question of whether, when a woman no longer has her reproductive capacity, she is still a woman (Holland & Adkins, 1996). The removal of ovaries from a young, premenopausal woman, results in the loss of reproductive potential. At the same time, the woman is thrust abruptly into the next stage of her life, often a number of years before she would have reached menopause naturally. She becomes, in the words of one of the respondents, a menopausal woman.
Yes most likely I will be a grandmother which is something the women in my family haven’t done. (Tearful) They haven’t been able to survive [13].

I’m thinking I don’t want to be carrying this gene. I have these little kids you know and because that was like three or four years, four years ago when [daughter] was only 12, I thought I couldn’t lose my life yet [17].

...when my sister went down with it, it was devastating. It was so devastating to us and it was like oh my gosh I’ve got a girl, well I’ve got two children. My sister’s got two girls… [18].

The majority of women in this study identified themselves as mothers in ways that clearly indicate the primacy of this role in their identity. While the definitions given above indicate that mothering involves the care of dependent children, the women in this study whose children are adults made comments that suggest that mothering and the identity associated with this role does not cease when children leave home.

I, yeah well see I have two sons… and so I thought right well I need to know [14].

This woman decided to have testing for a familial BRCA mutation because she wanted to be able to give the information to her adult sons. The women with adult children frequently expressed concern regarding their children’s cancer risk and whether their children were having genetic testing and appropriate surveillance, supporting the implication that maternal caring does not end as children enter adulthood. Other studies also support this finding (for example Dillaway, 2006; Hislop & Arber, 2003a; 2003b). Women in Dillaway’s (2006) study about the experience of menopause indicated that the role of mother remained their primary identity even when their children were adults. They continued to put the well-being of adult children above their own well-being, in ways that are also discussed by the women in this study. Dillaway (2006) suggests that
mothering ideology reaches deeply into women’s lives, shaping their identities and choices. She goes on to say that “motherwork perhaps never wanes: once women are mothers, they are always mothers, and they are always impacted by mothering ideology” (Dillaway, 2006, p. 51).

7.1 Gendered constructions of mothering

We live in a gendered society where notions such as femininity and womanliness are designed to fit people into social roles such as “mother” (Lorber & Moore, 2007). From a very early age, children develop an understanding that the world is gendered (Holmes, 2007; Murachver, 2006). Children self-select activities they deem to be acceptable to their gender, developing skills in those activities and engaging in the process of social construction of gender. Girls are socialised to be the carers for our society, brought up to assume care-giving responsibility for others, particularly those they are closest to, their partners, children and extended family. The women in this study experience their lives as mothers, partners, daughters, sisters and friends, roles which are central to the construction of femininity and womanliness in Western society. Indeed, there are suggestions that a woman’s identity is entwined with her capacity to care for and nurture those around her (Murphy, 1999). In discussing the work of psychoanalytist Nancy Chodrow, Mary Holmes (2007) notes that Chodrow believed that girls learn from their mothers that “being feminine means nurturing and caring for others” (Holmes, 2007, p.34, emphasis added).

The role of mothering is associated with women because it has traditionally been women who have taken on these tasks (Arendell, 2000). Mothering and femininity are entwined, with the role and tasks of mothering reinforcing women’s gender identity. Dominant political forces contribute to society’s understanding and expectations regarding gendered roles and responsibilities. The place of women as carers and mothers was reinforced through State imposed laws, beginning late in the nineteenth century, that defined family and gender relationships in ways that influence New Zealand society still (Park, 1991). Women were encouraged to remain at home and their skills as housewives were recognised. During the first decades of the twentieth century political ideologies such as the “family wage” reinforced the place of women in the home and as the unpaid provider of care for children, people who were ill, elderly or
disabled. The expectation that women will provide unpaid care for their children and families continues through to the present day. Bordo (1993) contends that culturally, women are cast as the chief nurturers, providing both physical and emotional nurturing to others. She believes that as a result of their cultural socialisation, women develop a totally “other-oriented” emotional economy, and learn to limit and constrain their hunger for independence and a meeting of their own needs and desires (Bordo, 1993).

Recent trends have indicated that there may be starting to be a shift in the positioning of women and mothers at the centre of domestic life, with some women no longer finding this position relevant. However, in their ethnographic study examining the experience of being obese in the context of women’s daily lives, Warin et al (2008) found compelling evidence that women continue to be the nurturers and to care for the needs of others, namely their children and partners, before caring for themselves. For example, they often lack time and opportunities to exercise because of their care-giving duties. Studies exploring the social context of sleep also support the observation that women prioritise the needs of others, particularly their partners and children, above their own needs (Hislop & Arber, 2003a; Hislop & Arber, 2003b; Kirkman, 2010; Venn et al, 2008). As studies by Hislop and Arber (2003a) and Venn et al (2008) have shown, women continue to fulfil their responsibilities as carers throughout the night, providing both physical care for young children, and emotional “care” for children of all ages. The finding that women stay in violent relationships until such time that they no longer believe that their children are safe (Kelly, 2009) further supports the evidence that women continue to put the needs of others, particularly their children, before their own needs and indeed safety. These studies all describe the gendered nature of caring, highlighting both the physical caring activities that women undertake along with the sentient or emotional activities of caring for their families.

Research suggests that women from hereditary breast and ovarian cancer families assume responsibility for genetic risks for themselves and for their family members (Hallowell, 1999b). In a study of women attending genetic counselling, Hallowell (199b) found that women reported that they felt obliged to manage their cancer risks, with these obligations arising out of their relationships with both relatives who had died of cancer and those living relatives for whom they felt a duty of care. The women in Hallowell’s study reported that their decisions regarding risk management were constrained by feelings of duty and responsibility, particularly toward their children.
7.2 Motherhood and Responsibility

Women are perceived as having ways of being that are relational and connection-oriented, making them ideally suited for the relational aspects of child-rearing (Oberman & Josselson, 1996). Oberman and Josselson (1996) suggest that motherhood has multiple and shifting meanings for women, with women experiencing conflicting meanings at times. In an example that is particularly relevant for the women in this study, they describe the way that mothering confers maternal power and at the same time “an immense burden of responsibility” as they are expected to live up to the myth of the omnipotent or good mother that is so present in societal constructions of mothering (Oberman & Josselson, 1996, p. 344).

In a study that revisited the critique of medicalised childbirth Fox and Worts (1999) suggest that motherhood is a private responsibility rather than a responsibility that is shared by a community. They believe that the model of women birthing in hospitals and with limited social support makes the private or individual responsibility of the woman-mother to her child very obvious. Societal messages regarding the private responsibility of individual women to their children provide significant challenges for many women at different times during their lives. For women with an inherited cancer risk the burden of this responsibility appears to be particularly strongly felt and articulated by several of the women with young children interviewed for this study. As is evident from the earlier quotations, the women in this study identify a responsibility to remain alive to see their children grown, a tangible responsibility that involves the women in making challenging choices about their own bodies. Many of the women who had watched their own mother become ill and face treatment for cancer were very clear that they did not want to put their own children through this experience.

Worst case scenario, if I was the same age that Mum was when she got first diagnosed, my eldest child would be nine where Mum’s eldest child was 17 so it’s quite different. I’ve had my children later in life than my parents; my children might have their children later. If I passed away at the same age as Mum I’d be lucky to see my children’s
21st birthdays let alone see grandchildren. I just think what we’ve been through with mum and I don’t really want to have to put my husband and children through that [3].

I felt if I left it – because of personal or vanity reasons – and I subsequently developed breast cancer I would have never forgiven myself – why put my family through it? [19].

Motherhood in contemporary Western society has at its heart “an ethic of caring – of knowing, feeling, and acting in the interests of others” (Forcey, 1994, p. 357). In choosing to have genetic testing and risk reducing surgery, the young mothers in this study are living out the ethic of caring, acting in their own interests and at the same time acting in the interests of their children.

Several of the older women with adult children, nieces and nephews, indicated that much of the work they had done in seeking a genetic assessment was for the next generation rather than for themselves. As one woman who had spent some time collecting family history information said:

I’ve been to the geneticist and I’ve done, I’ve said I’ve done quite a lot of groundwork for the next generation... [32].

The finding that women request a genetic risk assessment because of a feeling of responsibility to the next generation is supported by several other studies. Rowley (2007) interviewed twelve women about the decision to undergo BRCA genetic testing and found that the women’s decisions were heavily influenced by their sense of responsibility towards other members of their families. The women in Rowley’s (2007) study decided to have testing to clarify the risk for their own children, and to reduce the chance that their own family would have to watch them become ill with cancer. Along with earlier studies (Hallowell, 1999b; Hallowell et al, 2003; D’Agincourt-Canning, 2006), Rowley (2007) describes the decision to undergo testing as being influenced by their responsibilities towards others. Women in D’Agincourt-Canning’s (2006) study indicated that they hoped that genetic testing and subsequent medical management would help them to fulfil their responsibilities as parents. Women undergoing initial BRCA mutation searching drew on a discourse of responsibility when citing their
reasons for having testing (Hallowell, et al, 2003). These women, who had all had cancer themselves, saw providing a DNA sample for mutation analysis as providing them with a means of fulfilling their obligation to care for others in their family, particularly their children and sisters. Women in an earlier study by Hallowell (1999b) also drew on discourses of responsibility to others, including children, when making decisions about risk reducing surgery. For the women in the present study, the “others” to whom these women feel most responsible are their children, both young and adult. The finding that women are so strongly motivated to seek genetic testing and risk reducing surgery in order to remain well and fulfil their responsibilities to their children, in other words, to fulfil their responsibilities as mothers, indicates just how strongly the identity or status as mother is experienced by many of these women.

These women give accounts of themselves as caring and responsible mothers, drawing upon moral discourses that are prevalent in society today. As discussed in chapter four, the accounts were obtained through single interviews with each woman. Interviews are a form of interaction that involve the presentation of self (Cotterill, 1992; Ribbens, 1989), and it could be argued that the accounts given in these interviews reflect a desire by the participants to present themselves in a particular way, for example as “good” mothers.

While the present study involved interviewing women, other studies have either included men or have looked specifically at men from hereditary breast and ovarian cancer families (D’Agincourt-Canning, 2006; Hallowell et al, 2005; Hallowell et al, 2006; Lobb et al, 2009). For the men interviewed by D’Agincourt-Canning (2006) the results of the genetic testing had limited impact on their own health care. These men chose to have the testing to provide information for their daughters and granddaughters. The majority of men who responded to a questionnaire regarding their attendance at a genetic clinic reported that they attended at the request of a family member (Lobb et al, 2009). This study and an interview based study by Hallowell et al (2006) suggest that men place value on family responsibility and regard genetic testing for hereditary breast and ovarian cancer as a family duty. These findings reinforce the understanding of the familial context in which genetic testing is done and illustrate that genetic testing may be viewed as a parental as opposed to solely maternal responsibility. However, as Lobb et al (2009) found, the men generally attend at the
request of a female family member, supporting the strong sense of maternal responsibility identified in this study.

Several recent studies have explored the experience of mothering in the context of risk, including Barnes and Murphy’s (2009) research into the reproductive decision making of women who are HIV positive, Kelly’s (2009) study of intimate partner violence, Warin et al’s (2008) study of mothers who are obese, and Elmberger et al’s (2008) study of mother’s with cancer. Taken collectively, these studies explicate the ways that women use the fact of being a mother to facilitate the wish to live, to keep themselves and their children safe, and to hold on to hope for their future.

The findings of this study add to the literature regarding the experience of mothering when living with risk. This group of Pakeha New Zealand women living with an increased risk of cancer reflect similar feelings about living with risk. For many of the younger women in the study, the desire to be there for their children, to see their children grow up, and not to put their children through the experience of watching their mother ill with cancer, provide powerful motivating forces in their decision making about genetic testing and risk reducing surgery. As described in chapter six, the prevailing attitude for New Zealand women living with an increased cancer risk appears to be to “get on with it”. While the studies exploring mothering in the context of risk do not specifically describe the women as “getting on with it”, the ways in which women use their responsibilities as mothers to motivate safety and survival suggest that “getting on with” their lives as best they can may also be part of their experience.

7.3 Becoming a mother

My outlook has changed with now having my own child [3].

The transition to becoming a mother may influence a woman’s outlook regarding the possibility of an inherited predisposition to cancer in her family. As this woman comments, the birth of her son changed her outlook. Up until the birth, she and her sisters had chosen not to request BRCA mutation analysis using a DNA sample their mother had stored for this purpose prior to her death. When her son was born it became
more important that she try and clarify her own cancer risk and at the time of her interview she had begun to discuss with her sisters the possibility of using the stored DNA sample.

The women in this study manifest their identity as mothers in several ways. Women discussed their feelings about the possibility of passing on an inherited cancer risk regardless of the age of their children.

And the thing that upsets me I suppose with it is you know because I have a daughter and I don’t want anything to happen to her and it doesn’t mean it might not. But you know what sort of legacy is that you know [8].

Mothers of adult children who had had genetic testing and been found to carry the familial mutation expressed their sadness. Some of these women explained that the finding that they carry a cancer predisposition mutation makes them worried for their children and grandchildren rather than for themselves. Several women with adult children spoke about the importance of surveillance and their role in ensuring their adult children had surveillance.

I think it’s a wee bit concerning for my daughters and I must get the letter, I’ll get a copy of the letter photocopied and both their doctors want to put it on file because that was one of the recommendations that they have, one daughter’s 37 the other one’s 31, that they sort of make sure that they have some surveillance [12].

…just keep an eye on our children, our daughters, my sisters. Tell our daughters to have routine checks and things like that… [17].

…the way I understand it and certainly my children will be screened regularly from about 35 which is about now for one of them… [21].

Mothers of young children spoke about their hopes of not having passed on the mutation, and their hopes for improvements in surveillance and treatment in the future. As discussed in chapter five, the two women who were considering having children talked about the possibility of using assisted reproductive technology to avoid passing on the mutation, a choice that the other women in the study had not faced. Another area
in which evidence of the centrality of their role as mothers was very obvious was when women talked about the reasons why they were having risk reducing surgery, with many of the women with young children expressing a strong desire to be there for their children and to watch them grow up. Women who had watched their mothers face treatment for breast cancer when they themselves were still children expressed a strong desire not to put their own children through a similar experience. Finally, several women answered queries about sexuality and body image with comments regarding pregnancy and breast-feeding, demonstrating an association between women’s bodies and their reproductive, rather than erotic, capacity.

These women appear to view their role as a mother as their first priority and as the most important aspect of their lives, a finding that is supported by studies on diverse topics including obesity (Warin et al, 2008), menopause (Dillaway, 2006), sleep (Hislop & Arber 2003a) and intimate partner violence (Kelly, 2009). As one woman reported, her first thoughts after receiving her result were my initial thing was oh my kids, my kids [29]. Other women stated that they want to be around to see my kids grow up [19] and that they are just not taking chances [24] where their children are concerned. These women all have dependent children. Other studies of women with cancer (Elmberger et al, 2008) and women who are HIV positive (Barnes & Murphy, 2009) have highlighted the connection between having children and the wish to live, a connection which is also made by the women in this study. While carrying a cancer predisposition mutation does not make a diagnosis of cancer inevitable, several of the women in this study demonstrated a clear association between having dependent children and doing everything they could to ensure their survival. Women in Elmberger et al’s (2008) study reported that having children facilitated their desire to live and noted that the bond with their children was encouraging and mobilising as they went through cancer treatment. One of the women in this study named this feeling “mother power” (Elmberger et al, 2008) a term that could also be applied to the mother’s in this study, who attributed their decision to have risk reducing surgery to their status as mothers. However, while the mothers in Elmberger et al’s (2008) study re-defined their mothering to live in the present and enjoy their children now, the mothers in this study used their desire to be with their children in the future to motivate them to make difficult choices now. Women who are HIV positive also conceptualise motherhood as a reason for living, providing them with hope for the future (Barnes & Murphy, 2009).
The concern with survival in order to fulfil certain role responsibilities appears to be common among women in varying situations including women who have had a diagnosis of cancer, women who are HIV positive and women who have an increased risk of hereditary cancers (Barnes & Murphy, 2009; D’Agincourt-Canning, 2006; Elmberger et al, 2008; Hallowell et al, 2003; Roberts & Clarke, 2009). There are obvious similarities between living with an increased cancer risk due to an inherited predisposition and living with the risk of recurrence for women who have had a diagnosis of cancer. Women who have had treatment for breast cancer report feelings of fear regarding the possibility of a recurrence of their breast cancer. In a small interview study of women who had undergone mastectomy for breast cancer, Crouch and McKenzie (2000) found that women were concerned with the dangers that lay within their bodies, unseen, but present in their daily thoughts. Hallowell (2000) found that women with a family history of breast cancer were also concerned about the unseen dangers that lay within their own bodies. Similarly, Roberts and Clarke (2009) describe the challenges of living with the risk of recurrence after a diagnosis of gynaecological cancer. Single mothers found living with the possibility of cancer recurrence particularly burdensome. Common to all these studies and to the New Zealand women interviewed for this study, is the importance of survival in order to be able to continue to fulfil their responsibilities as mothers (and daughters and grandmothers).

The identification of a cancer predisposition mutation may raise questions regarding whether a woman should become a mother. The women in this study live in a society within which there is an implicit understanding that most women should be mothers (Lorber & Moore, 2007). At the same time they live in a society within which questions are raised regarding whether individuals should knowingly pass on a genetic mutation, particularly given the availability of technology to reduce this possibility (Menon et al, 2007; Steinberg, 1996; Williams et al, 2007). While Fox and Worts (1999) suggest that the messages regarding maternal responsibility are reinforced at the time of labour and delivery, a few of the women in this study indicated that maternal responsibility may precede conception for some women who carry cancer predisposition mutations. Two women specifically raise the matter of using pre-implantation genetic diagnosis to avoid passing on the mutation to their child. Several women were still having children at the time of their interviews, and two women were undecided about whether or not they would have children. The knowledge that one could potentially pass on the risk of
cancer adds a new dimension to the decision making about becoming a mother. As one of the women who was considering whether or not to have a child says:

...there’s not a lot of understanding and that’s the reason why I didn’t tell anyone because when I first met the ob/gyn I spoke about this fear of being judged about it and I didn’t want someone to say well you’ve got the BRCA gene you can never have children and that’s why I didn’t tell anyone [16].

Another woman who has three young children talks about another family member who thought that carrying the familial mutation would preclude her from having children:

I mean one cousin when she was tested for the BRCA gene it was really hard on her. She said “you know if I’ve got it I wouldn’t have children” and I felt that’s really sad. I just felt oh, that would never even have crossed my mind [19].

Women who are HIV positive face challenges that are, in some ways, similar to women who carry a cancer susceptibility mutation. In recent years HIV has shifted from being a fatal condition to being an often controllable chronic condition. Both women with HIV and women with cancer predisposing mutations carry the potential seeds of their own demise within their bodies. Both HIV positivity and genetic mutations can be passed on to children. Both groups of women appear to face similar conflicting societal messages. Barnes and Murphy (2009) report that women who are HIV positive struggle with conflicting societal messages that say that most women should be mothers, and that women who are HIV positive should not have children. Several women in the present study also describe their awareness of the potential conflict regarding the acceptability of having children.

The centrality of the role of mother for many women can result in implicit social pressure to have children. A twenty-five year old woman who carried a Lynch syndrome mutation and was at increased risk for endometrial cancer talked about discussing a hysterectomy to reduce this risk. She says several times during the interview that she does not think she wants to have children, but she has encountered reluctance to proceed with a hysterectomy at this age:
I don’t really think I want my own but at the same time people go oh well you’re only 25 and you say okay I can understand that. So yes I am happy to sort of wait till I’m older to decide whether to have a hysterectomy or not, definitely. I wouldn’t just sort of jump in and do it and regret it later unless I had to [28].

Women with known cancer predisposing mutations can potentially avoid passing on the mutation by accessing assisted reproductive technology. As discussed in chapter five, two women were considering using pre-implantation genetic diagnosis to avoid passing on the increased cancer risk to their children. Rowley (2007) explores women’s accounts of their decisions to undergo BRCA genetic testing in light of recent requests to the British Human Fertility and Embryology Authority for permission to use pre-implantation genetic diagnosis for BRCA mutations. She concludes that while this may be an extreme example of parental responsibility, it nevertheless highlights the significance of responsibility towards significant others that women from hereditary breast and ovarian cancer families experience. Suffice to say that the possibilities for women with an inherited cancer susceptibility afforded by new reproductive technologies deserve further exploration, particularly in light of the centrality of concerns regarding mothering identified by this study.

7.4 Mothering adult children: responsibility and obligation

The importance of staying alive to fulfil their responsibilities as mothers is paramount for the women with dependent children. The role of mother appears to continue to be important when children are grown, with the women articulating their concern for their children’s health and well-being and their distress when adult children are at increased risk of developing cancer. One woman states very clearly her mothering role with regard to ensuring her children, who are in their thirties, have surveillance:

...certainly my children will be screened regularly... they’ll be vigilant. I will be on to them to make sure they do regularly [21].

Other women talk about discussing the possibility of genetic testing with their adult children, again establishing their identity as a mother and in some instances as a grandmother:
I've got two sons, and I've told them they should get tested, but whether they get around to it I don’t know [22].

I have two sons but I have three granddaughters... I wasn’t so worried for me. I’m more worried for my son who’s got the three daughters [14].

Genetic testing for cancer predisposition is viewed by genetic health practitioners as an autonomous choice for each individual in the family. However, there is evidence in some of these interviews that women expect that their adult children will have testing one day. For example, when asked about whether her children would consider testing, this woman said:

Yep, yes… [Daughter] will have to go for it one day [1].

The collective message from these comments suggests that many of these women have an expectation that their adult children will have testing for the familial mutation and will then comply with surveillance recommendations. A number of studies have found that genetic testing decisions may be influenced by feelings of obligation to other family members (D’Agincourt-Canning, 2006; Etchegary & Fowler, 2008; Hallowell et al, 2003; Rowley 2007). Many of these studies have identified feelings of responsibility or obligation in relation to providing family members with risk information. Affected women describe feeling obliged to have BRCA mutation analysis to provide other family members with a means of clarifying their own risk and parents describe having testing to clarify the risks for their children.

7.5 Salpingo-oophorectomy and mothering

...I’ve got three young children and I know having my ovaries out reduces the risk... [24].

And I suppose that’s part of it too you know with having children you have to, you know like my daughter’s the same age that I was
when my Mum died and so (pause) yeah I didn’t want to head down the same track [6].

Motherhood confers conflicting messages regarding a woman’s sexuality. While sex and pregnancy are inextricably linked, when a woman becomes a mother her “sexuality is expected to go underground; motherhood and sexuality are split, and the mother is desexualised” (Oberman & Josselson, 1996, p. 354). For women with an increased risk of breast and ovarian cancer this split becomes tangible if they choose to manage their risk surgically. With the removal of her womanly parts these women are left feeling neutered. Many of the women interviewed for this study had chosen to undergo risk reducing salpingo-oophorectomy and/or bilateral mastectomy. The decision to undergo risk reducing surgery appears to be strongly associated with their responsibilities as mothers for many of these women. As the women quoted in the title of this chapter and in the opening quotations state, their decisions were directly related to their desire to be present in the lives of their children.

These women want to be there for their children, to watch them grow up. They are prepared to do everything they can to “get on with” managing the risk so that they can continue with their lives as mothers, partners, daughters, sisters, colleagues and friends. Some of them are prepared to tough out an early menopause if necessary. Others are using hormone replacement therapy both to protect their bones and cardiac health, and to mitigate the potential personality changes that concern them. A number of these women are very clear that survival and the ability to be there for their families are more important than personal reasons or vanity.

The role of mother is a socially significant one in many societies, as is the role of a woman as a wife or partner. Individuals have multiple contextual role identities (DeFrancisco and Palczewski, 2007). Most of the women interviewed for this study had husbands or partners and spoke in ways that indicated the importance of this role as part of their identity. The risk management options that these women face are intimately associated with both the role of mother and that of wife or partner.

In choosing to reduce their risk of both ovarian and breast cancer by having a pre-menopausal salpingo-oophorectomy, these women face the prospect of losing two of the
facets of themselves, their reproductive capacity and their physical attractiveness to men, that are valued by society. Several women acknowledge that their sense of self and of self worth is associated with these roles, with one woman saying that her sister has not quite been able to bring herself to have a salpingo-oophorectomy because of feelings of self worth [4].

Yes I do feel neutered. Yes I do feel neutered even though I know I am fully aware that there was never ever chance of me having any more children and that I had actually started menopause. It still did feel a bit that way and I think probably is why [sister] who knows, who has known a lot longer than me that she should be thinking about doing something like that hasn’t done and I’m pretty sure that’s why she can’t quite bring herself to do it, you know you know feelings of self worth [4].

The use of words such as neutered and eunuch to describe themselves after oophorectomy suggest that women are deeply aware of the meanings of the loss of reproductive potential, the loss of the possibility of becoming a mother.

Questions about body image and sexuality in relation to salpingo-oophorectomy received responses about child-bearing and pregnancy from several women, indicating that for some women their ovaries are intrinsically associated with reproductive capacity rather than with their own appearance or sexuality. For a number of women the fact of having had my children meant that having a salpingo-oophorectomy wouldn’t matter at all [32]. A woman with a toddler responded to a direct enquiry about whether body image and sexuality had affected her thinking about risk reducing surgery by telling the interviewer that she had loved being pregnant and the changes in her body that had occurred during pregnancy and breast-feeding. For those women who were in the midst of having their children, retaining their reproductive potential appeared to be their current priority. The association between questions about sexuality and responses related to child-bearing and pregnancy suggest that, for some women, the concept of female sexuality is intrinsically associated with the role of women as mothers. In this way the function of ovaries is associated with maintenance of reproductive capacity, with allowing women to fulfil their social responsibility to reproduce, to become a
mother. This group of young mothers also appeared to find it difficult to respond to the association between body image and salpingo-oophorectomy saying things like:

\[ \text{I mean having my ovaries and fallopian tubes removed once I've had children to me is no major} \] [3].

The felt responsibility to be there for their children is very strong for these women, particularly those with young children. The women who are making decisions about pre-menopausal salpingo-oophorectomy and risk reducing mastectomy are in their thirties and early forties, so they grew up in New Zealand during the 1970s and 1980s as neo-liberal thought and policy began to take hold. These women may almost take for granted the expectation that they will take responsibility for managing their own health. In taking responsibility for managing their cancer risk, they are also fulfilling their responsibility as mothers.

7.6 Mothering and the decision to undergo risk reducing mastectomy

To me the mastectomies had to be done to reduce my risk and so I would be around to see my kids grow up [19].

I've had my children; I've done my breastfeeding... [27].

Women who carry a BRCA mutation or who have a family history of breast and ovarian cancer may choose to reduce the risk of developing breast cancer by having a bilateral, risk reducing mastectomy. The women quoted above both chose to have a bilateral mastectomy and reconstruction after completing their families. The first woman describes her initial visit to a breast surgeon shortly after learning that she carried a familial BRCA mutation:

I had [daughter] when I first found out and I went down to my first visit, I went to see the breast guy first and I remember sitting there with my husband and [daughter] (inaudible) or something and him just
saying the only option is well basically breast off and that’s it. And I thought that was so (inaudible) I was so upset because I hadn’t finished having kids and I wasn’t anywhere near that stage really. Whereas yeah then I went and saw [gynaecologist] he was great, so great. The breast specialist, back the, gave me basically no other options, other than a mastectomy which was a bit much to take in given it was my first visit [19].

Over time, the BRCA mutation and the cancer risks it posed began to feel like a ticking time bomb and she decided that she wanted to be proactive about the breast cancer risk.

I just thought you know why wait I want to be proactive rather than wait until, I mean there was an 85% chance that I would get breast cancer so I thought really why wait and see if I’m one of the ones? [19].

She reiterates a number of times that she did it for the kids, voicing a strong desire not to put my family through it. She mentions twice that her breasts weren’t that attractive. Her statement that the surgery had to be done implies a felt imperative to manage her risk this way, rather than a “choice”. The words of this woman are used in the title of this chapter, as they perhaps best encapsulate the feelings of most of the women who have chosen to have risk reducing surgery when she says I just did it for the kids.

Four women, aged in their thirties and early forties, had undergone risk reducing mastectomy and two others, also in their early forties, were actively planning this surgery at the time of their interviews. Five of these women had children, the oldest of whom was twelve at the time of their mother’s surgery. All five of these women were clear that the motivation to have risk reducing mastectomies was strongly associated with their desire to be there for their children as they grew up. Another woman, who does not carry the familial BRCA mutation present in other members of her family notes that her sister had risk reducing mastectomies for her girls [15], adding support to the idea that it is the desire of the women in this study to be there for their children.

Managing the appointments and recovery from surgery can be challenging for women with dependent children:

... we’ve got kids to manage... [29].
I guess having breasts off I wasn’t really prepared for that I didn’t think I’d be quite so helpless, when I got home I just couldn’t anything… And I felt absolutely hopeless when I wasn’t sort of back into it and I was only just changing nappies by 4 weeks. I didn’t think the timeframe was realistic but I guess different people recover more quickly… Yes because there’s no way I could do much and because I’ve had this little scare, I sort of felt I didn’t want to do too much too soon, I think the feeling of absolute helplessness and nuisance and total reliance on everybody else was the biggest thing that hit me when I got home. It was just like I’m really healthy and now I am totally dependent on someone else to look after the kids.

The role and concomitant responsibilities of being “mother” are a pervasive presence in the interviews with these women. Mothers with cancer report having to juggle their treatments with their responsibilities as mothers and to search for a balance between being needed as a mother and allowing themselves to be ill (Elmberger et al, 2008). In the same way several women who have had risk reducing surgery talk about needing help with the children after their surgery and the difficulties of being helpless for several weeks after a bilateral mastectomy. These women appear to trade off the immediate responsibility of caring for their children with the longer term responsibility of remaining alive to care for them in the future.

Breasts have dual meanings, being culturally viewed as feminine and as sexual objects in Western society, and at the same time having a significant maternal element (Broom, 2001; Murphy, 1999; Stearns, 1999; Yalom, 1993). The women who have had risk reducing mastectomy appear to view their breasts primarily as maternal objects. When she says I’ve done my breast-feeding this woman is implying that she no longer needs her breasts because they have fulfilled their nurturing, maternal purpose. Studies of women’s intentions and experiences of breast-feeding demonstrate the tension between the maternal and sexual aspects of breasts. In an American study exploring the experience of breastfeeding, women were concerned that breast feeding be regarded as a maternal activity rather than a sexual activity (Stearns, 1999). These women were concerned that breasts and breast feeding were perceived by themselves and those
around them as nurturing and maternal not as a sexual activity. English women also described breast feeding as a private activity, one which should be done discreetly and in ways that would not offend the people around them (Murphy, 1999). Murphy’s (1999) work captures the discourse regarding the importance of breast feeding as being best for the baby and the act of a responsible mother. It is perhaps ironic that for the women interviewed in the current study, being a responsible mother extended beyond the act of breast feeding to the removal of healthy breasts once breast feeding was completed, in order to continue to fulfil maternal responsibilities. This finding supports the place of breasts as maternal objects as these women are sacrificing the sexual aspects of their breasts for the sake of their children.

7.7 Telling the children

In chapter five I described the different decisions these women identified themselves as having made during the course of learning about their inherited cancer risk. Among these they described deciding who to tell about cancer risk, including whether to tell their children, and what to tell them. The decision about what to tell the children and at what age about a hereditary condition has been explored in association with adult onset conditions including Huntington disease (HD) and hereditary breast cancer (Forrest Keenan et al, 2009; Holt, 2006; Tercyak et al, 2001). Previous studies have found that it is primarily the women in the family who take on the responsibility for passing on information about the inherited cancer risk (D’Agincourt-Canning, 2001; Forrest et al, 2008). In families where it is the man who carries the cancer predisposing mutation it also tends to be their wives or partners who are involved in passing the information on to their adult children (D’Agincourt-Canning, 2001). For most of the women in my study who had children still living at home, the decision to tell the children about the cancer risk and what they were doing to manage their risk appears to have been straightforward. A woman with two primary school aged children explains that both her partner and her children were supportive, saying

...yep very supportive of it and my kids were as well. I’ve kept them in the loop the whole way through [30].

Another woman, whose children are in their early teens says:
Well although we’ve been very open with her and you know the kids have been told when I went ahead with the oophorectomy and why. My daughter’s a clever girl I’m sure she’s figured out that you know she will have figured out some of the genetics involved but we haven’t discussed it specifically but we will as she gets older and yes if I could be tested and I knew I didn’t have the gene, then there wouldn’t be a problem for her and we know that we could forget that [6].

This approach is supported in the literature about Huntington disease, which suggests that children are more accepting of a hereditary condition in the family if they grow up with this knowledge, given in age appropriate ways during their childhood. Holt (2006) used a case study approach to compare two disclosure choices regarding risk status in families with Huntington disease and found that the now adult children involved in this study preferred early disclosure of their risk of developing Huntington disease and open and supportive family communication about the disease. Forrest Keenan and colleagues (2009) interviewed children and young people who had found out about Huntington disease in their family in several different ways and at different ages. They conclude that children and young people with a family history of Huntington disease want to know something about what is wrong with their affected parent and can cope with knowing at least some details from an early age. They suggest that knowing can ease children’s anxiety about inaccurate information that they may otherwise garner. The issues for families with hereditary breast and ovarian cancer are both similar, in that Huntington disease and breast/ovarian cancer are both adult onset dominantly inherited conditions, and different, in that risk reduction and surveillance options exist for families with hereditary cancer but not for families with Huntington disease.

Communicating with children about the finding of a BRCA mutation does not always appear to be as straight-forward as suggested by some of the women in this New Zealand study. In an American study about an education group for women with BRCA mutations, several women reported concerns about disclosing the result to children and had chosen to defer disclosure (Speice et al, 2002). In a survey of thirty-one women who carry a BRCA mutation, Segal et al (2004) found that approximately half the women had disclosed their result to their children. The children of the women who had not disclosed were younger, with most of the women in this group indicating that they thought disclosure should occur when children were in their late teens and early
twenties. However, Tercyak and colleagues (2001) completed a self-report survey with children (aged 11-17) of women undergoing BRCA mutation testing, most of whom had had breast cancer, and found that these children did not display elevated cancer worries or psychological adjustment problems. The children who responded to this survey were aware of their mother’s cancer diagnosis and the BRCA gene testing. More recently Bradbury et al (2009) conducted a qualitative, interview based study with the adolescent and young adult offspring of BRCA mutation carriers. The majority of the young people interviewed for this study reported no negative aspects to knowing about their risk of inheriting a BRCA mutation. In keeping with the literature on Huntington disease, these papers suggest that the key to successful adjustment in hereditary breast and ovarian cancer families is open communication. The findings of the present study indicate that open, age appropriate communication is occurring in at least some of the New Zealand families interviewed for this study.

Several of the women interviewed for this study indicated that they understood that the disclosure of information to younger children differs from disclosure to adult children. Most women with primary school aged children describe a process whereby the knowledge that their mother is well and is having surgery to reduce her chance of getting cancer is passed on to the children. Their interviews indicate a concern for the well-being of their children in knowing that their mother is healthy, rather than a process of specifically informing their children about their own risk at that age. The possibility of distressing young children is highlighted by the following comment in which a woman describes the anxiety her ten year old niece is experiencing:

*Unlike my sister who has two daughters the eldest one, oh she’s got a ten year old and a one year old, the ten year olds already paranoid that she’s going to get breast cancer and my step mum is just furious you know that she’s, she said to her oh when I get breast cancer will you come and help me and it’s like you’re ten you don’t even have breasts yet [27].*

This woman has chosen not to directly inform her own primary school aged sons saying:

*I haven’t told them. I mean they and I haven’t kept it from them, they know that we’ve been going to see these guys and these are
the decisions we are having to make. That and they know that I’m not ill so that’s fine [27].

There is still relatively limited research regarding the effect of growing up in a family with a history of cancer on children and adolescents. Matloff and colleagues (2009) suggest that the onset of puberty and the development of breasts can be a difficult transition for girls in families with hereditary breast and ovarian cancer. Parents face a complex time of both celebrating their daughter’s growing up and balancing their own concerns regarding her future health and well-being. Matloff et al (2009) speculate that a young woman may feel both the excitement of her maturing body and fear at the development of breasts, which she may already be aware of as sites of potential risk. In clinical practice it is not uncommon to hear women who carry BRCA mutations talk about the risk for their young daughters and to state that their daughter does not even have breasts yet. This highlights the contradiction that exists between the pleasure of watching one’s child grow up and the fear for their future which may accompany this. Women with BRCA mutations also sometimes comment on their desire to have sons rather than daughters. The effect of growing up aware of the possibility of an increased risk of cancer is an area that requires further research, particularly if it is true that open communication regarding the risk is occurring in many families.

Several women were hopeful that advances in medicine and technology would mean that their daughters had more options available to them when they reached adulthood.

I am counting on the fact that medicine’s moving pretty fast, that hopefully by the time she needs to make a decision then the testing will be better [6].

I have a daughter but she’s six. Twenty years before any decisions start impacting on her life [24].

Genetic testing for cancer predisposing mutations in the BRCA and Lynch syndrome genes is not offered to children as the associated cancers are not seen in children. Women of children who were too young to have testing articulated their hope that some or all of their children would not inherit the mutation:

And hopefully with my daughter won’t have it and if none of the boys have got it then it will stop [19].
The comments about the years until children will need to start making decisions regarding testing and risk management reflect both the hope that children will not inherit the mutation and the hope for medical advancements that will perhaps lessen the impact of the mutation for future generations.

The decision to tell children about the increased risk of cancer may be complicated by the views of different family members regarding this information being given to children and young people. One woman indicated that her wider family attempted to influence her decision to tell her teenage children that she carried a BRCA2 mutation:

That was a huge debate as well because the brother told me that if, that I shouldn’t tell my kids because and we had a long debate, big discussion about that. He was very, very strongly against telling the kids and I was, I was unsure in my mind. And he said if you tell your kids you know he will prevent his kids from talking with my kids because he doesn’t want my kids to tell his kids and, no it was really, I could see his point of view. He doesn’t want his kids to know, he feels very strongly about that. In the end I said no, I think that I need to tell my kids [10].

She acknowledges her own hesitancy in disclosing the information but decided to tell the children because in her family we like to know the truth indicating that she used the same principle to decide on the disclosure as she has used regarding other information. Other women also discussed the mixed feelings in extended families about telling children and young adults, with three women talking about over-riding the wishes of family members and disclosing the information to nieces and cousins. One woman described telling her nineteen year old maternal niece about the gene in the family as follows:

...for some reason her Dad was really adamant that he didn’t want her to be tested... She went to go and have the cervical cancer vaccine and she said the doctor knew the history of her mother and she said they referred her to the genetic clinic. I thought oh this marvellous, I said to her, “I’m going to talk to you frankly because you can understand and I will tell you everything”. I said “whether your Dad agrees with it or
not I actually think at 19 years you deserve to know”. So I told her the whole story. She knew nothing about gene in our family [26].

Genetic counselling for hereditary cancer usually includes discussion regarding telling family members about the increased risk for cancer. Genetic counsellors are sometimes asked about what and how to tell children about the presence of an inherited condition in the family. The literature regarding Huntington Disease is useful in informing discussions regarding talking with children about inherited conditions. This literature supports the view that children adjust to the information better if they are given age appropriate information and answers to their questions (Forrest Keenan et al, 2009; Holt, 2006).

There are a small number of inherited cancer predisposition syndromes in which genetic testing is appropriate during childhood or early adolescence. For example surveillance for Familial Adenomatous Polyposis (FAP) by colonoscopy starts from around age twelve. If a mutation is known in a family, it is appropriate to offer presymptomatic genetic testing rather than colonoscopy. Codori et al (2003) conducted a study that measured anxiety and depression in children at risk of Familial Adenomatous Polyposis prior to testing and at three time points after test results. They concluded that most children do not suffer from clinically significant psychological distress regardless of whether they have inherited the family mutation or not. Michie et al (2001) also reported that children did not show clinically significant distress in the year after genetic testing for Familial Adenomatous Polyposis. However they did note a trend for the thirty-one children with a positive test result to be more anxious and depressed than the twenty-nine children who had a negative result. Duncan et al (2008) interviewed young people aged between fourteen and twenty-six years who had undergone predictive genetic testing for Huntington disease or Familial Adenomatous Polyposis. They report a large range of effects, with harms and benefits associated with both positive and negative results. They conclude that further research is required to elucidate the harms and benefits of genetic testing for adult onset conditions in young people. The indication from these studies is that there are mixed results regarding the psychosocial impact of predictive genetic testing in children and young people and this finding is supported by a review article by Douma et al (2008).
The mothers of adult children in my study faced different experiences when disclosing the results of genetic testing. Their children may already be at an age where the information is of direct relevance to their health. A few of the women had adult daughters who had been found to carry the mutation. Some of them reported finding this news very distressing:

*My daughter came up positive, she was so upset. I was so upset for her* [22].

Another woman, who had had ovarian cancer and carried a mutation in a Lynch syndrome gene, talked about going to visit her daughter after she received her test result and said she thinks that the news did initially *affect her* [2]. She was reassured that her daughter will receive appropriate surveillance.

*She has been, she has had colonoscopies and everything already, they're onto it* [2].

For a woman in my study who carries a BRCA mutation and has two sons, it is her young granddaughters who she is concerned about. She explains that she does not get on very well with one of her sons and is concerned about his daughters. She reassures herself that her granddaughters are young at the moment and expresses a hope that she will be able to ensure the information is passed on to them in the future. This concern that the information will be lost over the generations is raised by several mothers, suggesting a feeling of responsibility not only to their children, but also to future generations, particularly their grandchildren. A woman with three sons in their twenties says:

*I have actually made a conscious effort to talk to my boys individually, not sitting down talking. God knows, you can’t do that, you get them while they’re there. But actually to tell them what is happening individually because it’s important for them to remember and pass it on* [4].

The experiences of these women suggest that they recognise the role of women and mothers as the keepers or holders of family information, responsible for ensuring that it is passed on through the generations (Richards, 1996).
7.8 Conclusion

Many of the women interviewed for this study were mothers. These women discussed living with the increased cancer risk in view of their felt responsibilities as mothers. Societal discourses suggest that most women will be mothers and that mothers have a responsibility to care for their children. These women indicated that they understood those societal expectations, particularly when they described their reasons for having risk reducing surgery. Most women with children still living at home were clear that one of the major reasons for proceeding with surgery was for their children. They were, in effect, living out the previously discussed desire to “get on with” managing their risk and living their lives. The findings from this study contribute both to the discussion about mothering in the context of risk and to the understanding of the responsibilities women perceive themselves as having when they consider genetic testing and risk management options. The findings expand the earlier work of Hallowell (1999b) in exploring the ways in which women draw on gendered discourses of mothering and responsibility to make and support their decisions regarding risk-reducing surgery. The following chapter explores the experience of risk reducing salpingo-oophorectomy and mastectomy.
Chapter Eight

Managing the risk with surgery

…I felt so vulnerable. I felt like I was going to have all my womanly parts taken off… [13].

These words were used by one woman to describe the devastation she experienced after receiving a positive BRCA1 predictive test. She speaks for many of the women in this study when she describes the feeling of being at risk and the potential means of managing that risk, the removal of her womanly parts, her breasts and ovaries, organs that, for her, are the essence of her identity as a woman.

Breasts and ovaries are potent signifiers of womanhood, creating a womanly look and feel as well as allowing a woman to fulfil reproductive expectations. Ovaries are, in many ways, seen as the essence of womanhood. They are responsible for producing the hormones that initiate puberty and the development of breasts and a body shape that signifies to the world that this person is a woman. They are potent in producing eggs, some of which will become our children. In this way a woman’s ovaries serve the function of allowing a woman to fulfil a societal expectation and become a mother. In the course of time the hormone production alters, egg production ceases and a woman enters a new phase of life as a menopausal and subsequently a postmenopausal woman. While biomedical models have traditionally viewed menopause negatively as a time of decay and “disease”, feminist paradigms view menopause as a time of transition, a time when a woman may face new challenges and also experience new freedoms as her children reach adulthood (Gannon & Ekstrom, 1993).

For women from families with hereditary breast and ovarian cancer, ovaries are both the essence of womanhood and a site of risk. For women with an increased risk of ovarian cancer, these small organs may hold the seeds of her own demise, even as they hold her reproductive potential. These women have a complex “relationship” with their ovaries. Many of them wish to become mothers, to realise the reproductive potential offered by the presence of ovaries and to fulfil societal expectations to become a mother. Once a
woman has realised that reproductive potential, once she has children, she is faced with a new responsibility. As discussed in the previous chapter, her felt responsibility now is to stay alive to raise her children, to be there for her children. In order to fulfil her responsibility as a mother, she may decide to have surgery to remove the site of risk, her ovaries. In doing so, she faces a threat to her sense of self, to her identity as a young, premenopausal woman. In choosing to have a salpingo-oophorectomy, she alters the timing and course of a life transition, bringing forward menopause, often by as much as ten years or more. She faces entering this life stage abruptly, rather than in the slower tapering off of hormone production that occurs naturally. While the surgery allows her to continue to fulfil her responsibilities to her children and family, for some women, particularly those who do not, or cannot, use hormone replacement therapy, the surgery comes at a cost. The cost is to her identity as a young, “feminine” woman. An ensuing renegotiation of her sense of self occurs after the surgery, as the menopausal changes occur.

Women who carry a BRCA mutation or who have a high risk of hereditary breast cancer may also consider the option of risk reducing mastectomy. This involves the removal of healthy breast tissue, usually followed by reconstructive surgery. Fewer women interviewed for this study have had, or were considering, risk reducing mastectomy than had had surgery to reduce the risk of ovarian cancer. This is in keeping with international studies finding that more women choose breast surveillance rather than surgery even in countries where risk reducing mastectomy is well-established and accepted (Metcalfe et al, 2008). The women who have had risk reducing mastectomy, or who were actively planning this surgery, talk about the decision and the aftermath of the surgery in much more detail, suggesting that it has had a far greater impact on them than salpingo-oophorectomy. As with a salpingo-oophorectomy, mastectomy involves removal of a body part (or parts) that is strongly associated with both sexuality, and femininity in Western societies. At the same time, breasts are maternal, providing an infant’s first source of nurturing. Risk reducing mastectomy therefore involves the removal of a central aspect of both femininity and of maternity for many women.

Many of the New Zealand women interviewed for this study expressed a matter of fact and pragmatic approach to managing their risk, particularly when it came to managing their risk of ovarian cancer by means of risk reducing salpingo-oophorectomy.
However, while they were prepared to have the surgery, in order to “get on with” their lives and to be there for their children, they voiced a number of concerns. This chapter discusses the experience of managing the risk of ovarian and breast cancer through risk reducing surgery, considering the impact of the surgery on the identity of these women as women, mothers and partners. The language used by the women suggests a distancing or separating of themselves from parts of their body that are perceived as dangerous. This is considered and compared with the language reportedly used by medical professionals when discussing salpingo-oophorectomy, which suggests that ovaries are simply dispensable body parts.

8.1 Surgical choices and medical recommendations

Fifteen of the women interviewed for this study have had a bilateral salpingo-oophorectomy. Five women were premenopausal at the time of their surgery (aged 38, 40, 43, 43 and 45). Three women were perimenopausal at the time of surgery and seven women were postmenopausal (one of these women had surgery after a diagnosis of ovarian cancer). Three other women (aged 33, 36 and 40) were actively planning surgery at the time of their interview. Another woman who described herself as perimenopausal indicated that she would be having a bilateral salpingo-oophorectomy once she became menopausal. Several women were still having children and talked about having this surgery once they had finished having children. Four women aged in their thirties and early forties had had a risk reducing mastectomy at the time of the interview, two women were actively planning this surgery and another young woman was considering having a contra-lateral mastectomy to reduce her chance of getting a second breast cancer.

The medical recommendation is that women who carry a BRCA mutation have a bilateral salpingo-oophorectomy (with or without a hysterectomy depending on whether they are considering the use of hormone replacement therapy or using Tamoxifen) when childbearing is complete and by approximately age forty (Haber, 2002; Society of Gynaecologic Oncologists, 2005). For the majority of women, this surgery thrusts them into an abrupt surgical menopause some years before they would reach menopause if no intervention occurred. The surgery may also increase the risk of cardiovascular disease and osteoporosis, both of which occur with greater frequency in postmenopausal
women. The use of hormone replacement therapy may be considered to ameliorate the effects of the surgery. However, hormone replacement therapy is associated with an increased risk of breast cancer, so may be contraindicated, particularly for those women with a previous diagnosis of breast cancer (Chlebowski et al, 2010). Some women were reluctant to use hormone replacement therapy or had been advised not to by their doctors because of the association with increased breast cancer risk.

I’ve heard from other people that it’s pretty rough and of course you can’t take hormonal treatment because it increases the risk, well my breast surgeon certainly wouldn’t like me to have hormonal treatment because it increases the risk of a breast cancer recurrence. So I’m stuck between a rock and a hard place [9].

Other women reported that they were using hormone replacement therapy to mitigate the effects of a surgical menopause, sometimes planning to wean off it gradually to simulate the gradual reduction of hormone production that occurs at menopause.

… it meant that I was going to have to take hormone treatment and then I have to weigh up the risk of hormone replacement with, yeah so there’s a balancing act there. At the moment I’m still on hormone replacement and I’m what now 43 and so I suppose I’ve been on it nearly five years so that might have to be reviewed… because then of course although my chances of breast cancer are already high because the genes seem to be linked, yeah but to me like I had one doctor that said to me you know get off this hormone replacement. But when I did a bit more research by having the oophorectomy I decreased my chances of getting breast cancer quite considerably anyway and so yeah. And I figure, I know it sounds silly, but I figure that if I do get breast cancer it’s more likely to be to do with my genes that it is to do with the hormone replacement and none of my relatives have died of breast cancer [6].

The efficacy of the salpingo-oophorectomy in reducing cancer risk in women with an inherited predisposition is well documented (Domechek et al, 2010; Kauff et al, 2002; Rebbeck et al, 2002; Rebbeck et al, 2009). The efficacy of risk reducing mastectomy is
also well understood (Domchek et al, 2010). However the effect of this surgery on a woman’s sexuality and body image is less well understood. The opening quotation encapsulates the dilemma for these women in that choosing risk reducing surgery means choosing to have all, or at least some, of their womanly parts removed.

8.2 Becoming a menopausal woman: Choosing to have a salpingo-oophorectomy

Yes it was a hard decision to make because yeah I suppose it’s all tied up with your sexuality and walking into the unknown. We’d finished our family so it wasn’t as if we wanted to have more children. But still, it’s still quite a big step. ...it wasn’t so much the body image but you don’t know quite what sort of effects it is going to have on you [6].

Almost half of the women interviewed for this study have had their ovaries removed. The women recognized the life-saving potential of the surgery, but raised concerns about the possible effects.

… my main worry about the ovarian side of things was going straight into menopause… [1].

I know the hormones will be a big issue… [27].

Well I mean you do feel a bit sad. You know like being away this weekend and there’s people there with babies and that and I think oh, but well yes [20].

I think I probably would consider having a hysterectomy but I think I’d rather get checked regularly. I think that’s a lot healthier because I could die in the operation you know what I mean. Yeah I don’t really, I don’t think I’d want to have the operation if there was other options [31].
Their concerns included both the physical and psychological impacts of oestrogen withdrawal, as well as the loss of reproductive potential and the potential for problems during the surgery. The younger women tended to voice more concerns about the effects of surgical menopause, however a few women who were peri- or postmenopausal at the time of surgery also voiced concerns about the potential effects. As the woman quoted above indicates, it is the uncertainty of the symptoms one might experience that the women found particularly difficult. A number of these women talked about the potential for changes to their personality and sense of self as a result of the surgery and subsequent hormonal changes. These will be discussed in the next section, and the physical symptoms of menopause will be discussed in the following section.

8.2.1 Concerns about changes in personality and identity

One young woman, with three small children, was planning surgery within a few months of the interview and was particularly concerned about the potential for negative changes to her personality. She was worried that she would turn into a monster [19]. Another woman, perimenopausal at the time of her surgery, was concerned about alterations to her feelings of self worth [4]. She described feeling neutered after her surgery. Another young woman talked about feeling as though she was going to become a eunuch [9] with the removal of body parts that were central to her identification as a woman. One woman affirmed the interviewer’s query about ovaries being about the core of your sexuality [12]. For a young woman who had menopausal symptoms after chemotherapy for breast cancer, the impact salpingo-oophorectomy would have on her general health and wellbeing rather than on her feminine identity or sexuality was a central concern. This woman had earlier commented that she felt that she was being attacked on all the, you know all the sexual parts of you [9], a comment that suggests an implicit understanding of the role of her breasts and ovaries in her identity as a woman.

The words of the women in this study suggest that being at risk and managing that risk through salpingo-oophorectomy poses a challenge to their identity as a woman, raising the possibility that they will feel neutered, and become a eunuch or a monster. When coupled with descriptions of the possibility of having one’s womanly parts removed the findings suggest that some of these women recognize their ovaries as playing a fundamental role in their feminine identity and their sexuality.
The ways in which individuals define themselves, both as individuals and as groups, become their identities. In the post-modern era, “self” is understood as a social construction that changes depending on the situation an individual is in, the group they find themselves with and their life stage (Grbich, 2004). An individual’s identity or sense of self has multiple facets, including individual qualities such as personality, intersecting group identities which include gender and national identities, and contextual role identities such as mother, partner, lover or friend (DeFrancisco & Palczewski, 2007). As Weedon (1987) says the “range of ways of being a woman open to each of us at a particular time is extremely wide but we know or feel we ought to know what is expected of us in particular situations… (p.86). That salpingo-oophorectomy may result in significant alterations to a woman’s sense of self, to her understanding of what occurs during each life stage, and to her feelings of femininity, self worth and womanliness should not be under-estimated. Identities develop as a result of societal interactions and an individual’s personal identities are socially bestowed and maintained. At its heart, “identity is about belonging”, giving an individual “a sense of personal location” (Weeks, 1990, p. 88).

The choice of the words *eunuch* and *neutered* reflects the concern expressed by another woman that the removal of her ovaries would result in her potentially becoming a man [32]. The term eunuch refers to male castration, resulting in a body that is more like that of a pre-pubertal male. The word neuter also refers to de-sexing and, again, is a term that refers to the de-sexing of male animals. These women indicate that they are aware of societal expectations regarding ways of being a woman, they know that women are expected to be feminine and they fear the possibility that they will lose their feelings of femininity and will instead feel like a *eunuch* or *neutered*, being neither fully feminine nor fully masculine. If identity is about belonging, these women are indicating that salpingo-oophorectomy may result in a feeling of displacement, a feeling of no longer belonging to the group identity that is “woman”. The use of words that are usually associated with male de-sexing is striking in light of the concern expressed by a woman in this study and by a woman in a paper by Hallowell (1998) about the possibility of becoming a man. However we do not have words to describe female de-sexing in the same way. Perhaps the biomedical model of menopause, with its connotations of aging and decay, is the equivalent to male castration.
In comparison, some women make comments that suggest that the thought of or the experience of salpingo-oophorectomy does not pose a challenge to their identity as women:

*I don’t have thoughts about body image with my uterus and my ovaries and things like that. That doesn’t matter because they’re not seen* [8].

*I don’t feel any less feminine or any less of anything* [25].

*I’ve read stuff that kind of said some people have a problem knowing that their ovaries have gone you know – no, not a problem at all* [29].

It is noteworthy that the woman who made the first of these comments also told the interviewer that she had not yet had a salpingo-oophorectomy because she did not want to become a *menopausal woman*. This contradiction indicates that the presence of functioning ovaries may in fact impact on her feelings about herself as a woman, although she did not directly articulate this.

The women who commented regarding the role of functioning ovaries on their gender identity voice varying views as to the significance of ovaries in making them feel like a woman. While some women consider that they do not *matter* because they are *not seen*, a view that echoes findings from earlier studies (Hallowell & Lawton, 2002; Meiser et al, 2000), other women commented on their sense of self worth and sexuality, their identity as women, being *tied up with* the presence of functioning ovaries.

Gender identity refers to an individual’s concept of themselves as male or female and to how much they associate themselves as feminine or masculine (DeFrancisco & Palczewski, 2007). The use of words such as *neutered* and *eunuch* indicate a fear of becoming not-woman, a fear of a reduced or altered sense of femininity. Gender is socially constructed, with both males and females encouraged by societal and cultural expectations to look, act and behave in ways that conform to the “norms” for their gender. Lorber and Moore (2007) suggest that we “live in a deeply gendered society” (p. 2) where the processes that produce gender difference are so taken for granted that we are rarely forced to consider the processes and behaviours that produce them. In considering the ways to manage their cancer risk, these women are forced to consider the influence of particular body parts, in this case their ovaries and breasts, on their
identity as a woman. At the same time, they must consider whether the absence of these body parts will make them somehow different.

Individuals experience their bodies and these experiences produce different senses of self (Lorber & Moore, 2007). Women’s experiences of menstruation, pregnancy, childbirth, breastfeeding and menopause form a part of their understanding of themselves as female, as a woman. These experiences form a natural part of a woman’s life, marking the passing of time as she moves from one life stage to another. Most women experience some or all of these events, creating a shared sense of identity, the group identity of being “woman”. While the experience of menstruation can be inconvenient at times, with several women commenting that they *don’t miss having my periods at all* [11], menstruation is a tangible, regular signifier of womanhood for many years of a woman’s life. It is also a potent reminder of a woman’s reproductive potential, regularly signalling her potential to reproduce, to become a mother.

### 8.2.2 Bringing forward menopause

Feminist paradigms of menopause view it as a life transition, a natural development, in the same way that the onset of puberty is viewed and celebrated as a natural life transition. Some of the women interviewed indicate that, while they are concerned about the effects of an earlier menopause, they are aware that menopause is a natural life transition that will occur at some stage.

*I mean the only thing that I’m probably worried about is the effect of menopause and I’d have to go through that* [16].

This woman’s comment indicates her awareness that choosing to have risk reducing surgery will alter the timing of menopause rather than whether it occurs or not. Women in other studies have also acknowledged that risk reducing salpingo-oophorectomy alters the timing of a natural event (Hallowell & Lawton, 2002). The women in Hallowell and Lawton’s (2002) study viewed a surgical menopause as being biographically disruptive, with the earlier-than-expected timing of their menopause causing them difficulties rather than the event itself.
The diagnosis of a serious illness such as cancer may result in feelings of disruption to an individual’s personal biography (Bury, 1982). One young woman who was found to carry a BRCA mutation after a diagnosis of breast cancer described the interruption to her life.

*I spent a lot of time grieving for the life that I have that I love that I have that had been interrupted and that’s taken me a long time to get over the chemo and it’s really only now some two and a half years later that I’m really starting to make tracks. I was in the middle of doing things... Dating this wonderful man who I’m marrying and we got interrupted and things just changed and developed in a different way than they would have otherwise, just differently* [9].

This sense of interruption was noted in a study of women with gynaecological cancers, who reported needing to re-orient themselves towards the future after completing treatment (Roberts & Clarke, 2009). In the same way, learning that one is at increased risk of developing certain cancers may result in a similar biographical disruption and future reorientation. People come to the experience of illness with biographical resources that influence the ways in which they respond (Zinn, 2005). These influences include experiences that people may have hoped for, as well as those that they have experienced. As one woman in this study notes, *it was difficult because I thought well it means I can’t have kids...* [15]. While she was in her late 40’s at the time of the salpingo-oophorectomy and was not really expecting to have children, the experience of salpingo-oophorectomy brought home the reality of this disappointment to her. For a number of women in this study salpingo-oophorectomy brought forward the timing of menopause, resulting in a period of re-orientation as they became a *menopausal woman*.

8.2.3 The physical changes associated with menopause

*I was 40 years old at that stage; I didn’t want to become a menopausal woman at that time* [8].

The words of a woman with a high risk family history of ovarian and breast cancer state all too clearly the dilemma some of these women face. She describes having a
hysterectomy for reasons that were unconnected to her family history of cancer. She chose not to have her ovaries removed because she did not want to become a *menopausal woman* at the age of forty. What does it mean to become a *menopausal woman*? The image that this statement conjures up is of a woman aging before her time, becoming something that most forty year old women are not. The words of women concerned about becoming a *monster* and not being quite sure about *what sort of effects it’s going to have* suggest concerns about changes both in personality and in the physical self associated with menopause. For several of the women interviewed for this study, the early transition into menopause after risk reducing surgery results in a period of re-negotiation of their sense of self and their identity as a woman.

Menopausal symptoms can have a significant effect on a woman’s day to day life regardless of whether menopause occurs as part of a natural life transition or as a result of surgical intervention. Surgical removal of the ovaries results in acute hypoestrogenism and hypoandrogenism, whereas in women who experience a natural menopause the ovaries continue to produce testosterone and androstenedione which are converted to oestrogen peripherally (Hendrix, 2005). There is some evidence to suggest that an abrupt surgical menopause is associated with significant symptoms because it is associated with a rapid reduction of oestrogen and progesterone in comparison to a gradual reduction occurring over time (Dennerstein et al, 2005; Hendrix, 2005).

Symptoms of menopause include climacteric symptoms (hot flushes and night sweats), loss of libido, vaginal dryness and pain with intercourse, sleep disturbance, migraine headaches, mood changes, and cognitive changes such as forgetfulness and loss of concentration. Lack of energy was also a commonly reported and distressing symptom in a recent study of perimenopausal women (Twiss et al, 2007). One woman who had a salpingo-oophorectomy aged 39 describes her experience:

*Hot flushes which I have about twenty times a day, about eight times every night. My partner’s rigged up a remote control switch for the fan which is at the other end of the bedroom so now I just hit the remote. Cool down turn it off again. (Laughter) ...gosh you feel like you’re absolutely burning up. I mean you can’t just lay there you’ve got to get off your back, you just feel like your back’s burning* [30].
While she does not specifically comment on the sleep disturbance, waking as a result of the climacteric symptoms appears to be occurring. This woman has two primary school aged children and a busy job, so the impact of the disturbed sleep resulting from being woken by frequent night sweats may be significant. Several other women also mention hot flushes and sleep disturbance:

- *I’m in the middle of menopause and hot flushes and so on, no sleeping at night [4].*
- *I’ve been forced into menopause... the hot flushes and all of that sort of thing, that you have to deal with [25].*

### 8.2.4 Changes in sexual relationships

Talking about sex was difficult for some of the participants in this study, as discussed in chapter four. Only one woman spontaneously told the interviewer that pre-menopausal salpingo-oophorectomy is *tied up with your sexuality* [6]. Two young women talked in some detail about the alterations in their sexual relationship with their husbands after surgery (see below). The possibility of changes in sexual experience is the result of several different mechanisms. The absence of ovarian hormones results in a thinning of the vaginal wall and vaginal dryness, affecting sexual response (Shell, 2006). Libido is also affected by menopause for some women. Women who have a hysterectomy as well as a salpingo-oophorectomy in order to be able to use hormone replacement therapy without the risk of endometrial cancer may experience an alteration in sexual response after the surgery. The uterus is involved in each stage of female sexual arousal, with removal altering orgasmic response. Therefore, after a salpingo-oophorectomy (and hysterectomy) women may not feel like having sex, and when they do have sex it may not be as pleasurable as it was prior to surgery.

One of the women discussed above says she is *not totally interested* [30] in sex at the moment and another woman talks about the changes in her marital relationship as a result of having a pre-menopausal salpingo-oophorectomy:

- *...once I had my ovaries out we pretty well stopped even though there was no scar to speak off I just (pause) and it’s something I’ve never felt really comfortable pursuing, partly because I am*
absolutely completely uninterested in sex myself at this stage. I feel like a hypocrite for suggesting something that I’m not wildly enthusiastic about although when we have it I think oh yeah that’s right, I like that. And he never pushes me and I don’t actually know whether that’s because he’s not interested because I’m not shedding off pheromones or because he’s not interested because he’s a man in his stage of life and then whether he’s not interested because he suddenly finds me incredibly unfeminine. And I don’t particularly want to go there.

For this woman, changes in her physical self as a result of the surgery have resulted in very real fears about whether her husband still finds her feminine. As Coward (1992, p. 152.) says, for many women there is a “... deep sense of self that attaches to the construction of the feminine sexual being as one who is desirable to men”, with sexual attractiveness being a value of central importance to many women (Stotland, 2002). As a result of the surgery, this woman is questioning her desirability to her husband, and perhaps also questioning the sense of self that is part of this. She specifically refers to the fact that she had very little outward evidence of the surgery. The changes are in her lack of interest and her fear that he finds her unfeminine. If sexuality is constructed as a pervasive aspect of our total self, the questioning regarding desirability and femininity that is occurring for this woman as a result of premenopausal salpingo-oophorectomy may be influencing her sense of self and her identity as a woman.

Another woman talked about it being a case of working at it [30] after her salpingo-oophorectomy at the age of thirty-nine. In choosing to manage their risk surgically these women have faced disruption to a significant and potentially important aspect of their adult lives. However, there is some evidence to suggest that, while menopause may have detrimental effects on sexual intercourse in relation to symptoms such as vaginal dryness and a lack of desire at times, many women anticipate and enjoy sex after menopause (Dillaway, 2005b). The women in Dillaway’s (2005b) study enjoyed the freedom from fear of an unplanned pregnancy and talked about increased sexual confidence and energy. While some of the women reported fluctuating difficulties with vaginal dryness and varying sex drive, they viewed themselves as sexual beings and addressed the difficulties with their doctors. Women in Hallowell et al’s (2004) study also reported more relaxed, laid back sex as a benefit of salpingo-oophorectomy,
indicating that sexual difficulties may be temporary, or limited to some women, and are likely to be able to be overcome. Winterich (2003) has suggested that other factors including the quality of a woman’s relationship and the couple’s ability to talk about sex may have a significant impact on a woman’s satisfaction and enjoyment. This is borne out by the statement that it is a matter of working at it [30]. As discussed in chapter five, women reported receiving limited information on the impact of pre-menopausal salpingo-oophorectomy and surgical menopause. Information regarding strategies for discussing concerns with partners and practical information about matters such as lubrication may be useful for women during surgical planning.

8.2.5 Weight gain and aging after premenopausal salpingo-oophorectomy

The only problem is I put on weight. I’ve put on about three or four kilos [26].

Weight gain is associated with menopause. Two women mention having put on weight after having their ovaries removed. The woman who is uninterested in sex and is concerned that her husband finds her unfeminine, talks about having put on about nine kilograms since the surgery. She describes the effect of this, saying...you know I was just getting more and more and more distressed because I had no idea what was going on... [24], suggesting that she may not realise that weight gain is associated with menopause for some women. Her experience suggests that considerable changes have occurred as a result of her surgery, with a resulting re-negotiation of self required. Concerns regarding weight gain and feelings of loss of control of a maturing body occur for many women at the time of menopause (Coward, 1992). Rosalind Coward (1992) found that many of the women she interviewed struggled with the weight gain that accompanied menopause, feeling that in order to be sexy, to be seen and wanted by men, they needed to maintain a body that fitted with the prevailing aesthetic demands for slimness and youthfulness. Dillaway (2005a) also found that women wanted to maintain an unchanging feminine body during and after menopause, finding changes such as weight gain problematic. Coward (1992) believes that Western society places little value on older women and their maturing bodies, which may be of concern to women who face the prospect of accelerating this process in order to reduce their risk of developing ovarian cancer.
Hallowell & Lawton (2002) also found that women are concerned about becoming “old” women as a result of having their ovaries removed to reduce the risk of ovarian cancer. In societies where aging sometimes seems steeped with negative connotations, with a loss of attractiveness, youthfulness and vitality, the decision to bring this process forward by having a salpingo-oophorectomy is a complex one. These women are in the midst of what may well be the busiest and most productive years of their lives, mothering their children and often working to help support their families.

8.2.6 Alterations in feelings of femininity

Bartky (1998) reminds us that femininity is a form of artifice, produced by disciplinary practices that aim to produce a body of a certain size and configuration. As women get older, it becomes increasingly difficult to maintain a body that is recognisably “feminine”. The women interviewed by Dillaway (2005a) indicated their desire to “look good”, which was related to maintaining an unchanging appearance. Changes in their physical bodies such as weight gain, skin changes including growth of hair on their faces and breasts, and sagging breasts were all viewed as problematic (Dillaway, 2005a). These changes were constructed as a change from a feminine, gendered body to an androgynous body, which they equated with invisibility and undesirability. For women who have premenopausal salpingo-oophorectomy, surgery caused an acceleration of a natural event, challenging the self-identity of these women as they struggle to accept a body that has become difficult to control, a body that is less feminine than prior to the surgery. As mentioned previously, one of the women commented on the need to be on hormone replacement if she were to have her ovaries removed in order to keep me from becoming a man [32]. This comment suggests she views the changes in women’s bodies that occur as part of the menopausal transition as resulting in a body that is less feminine/more masculine than previously. The loss of hormones at the time of salpingo-oophorectomy has also contributed to the fear of being viewed as unfeminine for the woman discussed above. Female hormones either naturally produced by the body or in the form of hormone replacement therapy, are therefore seen as playing a role in maintaining a body that is recognisably feminine. These comments suggest that, for some women, the presence of functioning ovaries is associated with production of a body that looks recognisably feminine.
Prior feelings about one’s body may also contribute to a woman’s feelings after salpingo-oophorectomy. In considering a question about how she would feel about her body if she had her ovaries removed, one woman says *I feel kind of feel androgynous. I’ve never felt... I’m not a girly girl.* [31]. For women who already see themselves as being less feminine than their peers, or who place a lower priority on the way they look, the impact of the surgery on their sense of self may be different compared with women who pride themselves in looking feminine. Another woman who competes in triathlons regularly was due to have surgery a few weeks after her interview. She was aware that the *hormones will be a big issue.* She went on to say *I do a lot of sport and I just think hopefully that will just keep me going* [27]. Using sport to *keep me going* was a central theme in her discussion, with the ability to use her body to train and compete viewed as more important than the possibility of physical changes to her body after the surgery.

### 8.2.7 Ovaries are not seen: alterations in look after salpingo-oophorectomy

There are suggestions in the literature that women find the decision to have a salpingo-oophorectomy easier than the decision to have a mastectomy because ovaries are hidden from view and, with laparoscopic surgery, the scarring will be limited (Hallowell & Lawton, 2002; Meiser et al., 2000). The women interviewed for Meiser et al.’s (2000) study considered that removal of the ovaries in women who were postmenopausal or who had children, did not affect femininity because ovaries are unseen. Women interviewed for Hallowell and Lawton’s (2002) study did not see salpingo-oophorectomy as a threat to their body image because the surgery did not involve the removal of visible body parts. A woman in the current study also reported that salpingo-oophorectomy did not matter because ovaries were *not seen*. However, women in this study and in Hallowell and Lawton’s (2002) study reported concerns about physical changes after surgery, including weight gain, altered body shape, the appearance of wrinkles and other physical changes that they associated with aging. These findings indicate that, while ovaries might be hidden from view, the effects of the loss of the hormones they produce are visible and result in alterations to the way that a woman looks. In this study, the descriptions of weight gain, of fearing that one’s partner regards one as *unfeminine*, of being *neutered* or a *eunuch*, of being concerned about *becoming a man*, and of being *not totally interested* in sex, suggest a significant threat to the body
image and sexuality of these women. The absence of a symbol of femininity and reproductive capacity in the form of menstruation may compound this threat. The physical changes that occur in the months and years after surgery and the fears about feeling unfeminine, particularly in the absence of hormone replacement therapy, pose a threat to the identity of these women in a way that has not previously been recognised as impacting on the way a woman looks.

Two women talked about how upsetting they had found having a hysterectomy years earlier, suggesting that for some women their uterus and ovaries are important in their identity as women regardless of whether they are seen or unseen.

... I had a hysterectomy when I was only thirty two... Yes I always remember my doctor who was a male at that time, he was young, probably like only five or ten years older than me at the time, and he said that to me, it’s like a menopause I suppose. Of course that was the thing I think I did all that then because going through it now because having the ovaries still there you go through the menopause but I sort of sailed through it really, whereas I was terrible when my hysterectomy was first done. I was crying all the time and that sort of thing, my doctor said that was because I felt less of a woman. I said to him at the time, no. I said I don’t miss having my periods at all [11].

I’d had a hysterectomy and that really, that really upset me, the reaction to that was umm.... it took me a long time to come to terms with that. And even then you know when I was having that I was very keen because I didn’t want my ovaries removed then because it would have been just too much, too much sort of you know. It’s a bit silly I suppose really... [12].

The removal of a woman’s ovaries or uterus results in the loss of reproductive potential. As suggested by the doctor of one of these women, the removal of her uterus may have made her feel like less of a woman. Hallowell (1998) suggests breasts are important because they make a woman look like a woman, whereas ovaries are important because knowing that they are there make a woman feel like a woman. The comments by the women who had found having a hysterectomy very upsetting contribute to the
observation that, for some women, having internal reproductive organs is important to a woman feeling as though she is still a woman, with a woman’s capacity to fulfill her reproductive role. The comment by a woman in her late forties who found the decision to have a salpingo-oophorectomy difficult because it meant that she could no longer have children supports this observation. However, there are suggestions in this work that for some women, bodily changes that occur after salpingo-oophorectomy alter the way they look as well as the way they feel. In this way, ovaries may also be important in helping a woman look like a woman.

8.2.8 Menopausal symptoms associated with chemotherapy

Chemotherapy can precipitate menopause for some women. Two of the women in this study who had had breast cancer mentioned this. One woman was fifty when she was diagnosed with breast cancer meaning that she experienced menopause close to the age when she might reasonably have been expecting it. She comments that she found the decision to have her ovaries removed straightforward primarily because she was already experiencing menopausal symptoms. The other woman, diagnosed with breast cancer aged thirty-four, was not expected to become menopausal as a result of her chemotherapy. Along with the breast cancer diagnosis and the subsequent finding that she carries a BRCA1 mutation, she lost the ability to have children. At the time of her interview she was considering having a salpingo-oophorectomy, but was reluctant to proceed because she thought that her ovaries were perhaps still functioning in a limited way and she was concerned about being thrust fully into menopause. She is particularly articulate about her decision making process and her comment illustrates the complexity of the decision to proceed with risk reducing salpingo-oophorectomy, at least for some women.

... although I’m in menopause now, and I’m sort of getting menopausal symptoms I suspect that my ovaries are still kicking over a little bit, so with my ovaries out you get thrown suddenly holus bolus into menopause which I’ve heard from other people that it’s pretty rough [9].
8.2.9 Risk reducing salpingo-oophorectomy in women who are postmenopausal

In comparison with younger women, the decision to proceed with a risk reducing salpingo-oophorectomy appears to be more straight-forward for women who are post-menopausal when they learn about the increased risk of ovarian cancer.

*He simply said you know ovarian cancer is a silent killer, and what have I got to lose at my age* [14].

*No, couldn’t get it out quick enough. I thought if that was a site for cancer take it out it’s served its purpose. Absolutely not an issue at all, really it’s not* [21].

These women aged sixty and fifty-six respectively, both make comments that suggest that having their ovaries (and uterus in the case of the second woman, who has Lynch syndrome) removed is the sensible thing to do. The majority of postmenopausal women interviewed have had their ovaries removed and none of them mention problems associated with this. This is in keeping with the study done by Meiser et al (2000) which included eight women who were post-menopausal at the time of salpingo-oophorectomy. They viewed their reduced libido as an effect of menopause, rather than attributing it to the salpingo-oophorectomy, which came after menopause.

8.3 Choosing to have a risk reducing mastectomy

*...I like my breasts just the way they were...* [9].

*I’m particularly fond of my breasts that’s why I didn’t chop them off...* [10].

*I thought these are mine... I couldn’t do that to myself...* [15].

*My boobs are quite important to me* [18].
The decision to have a risk reducing mastectomy came about in different ways for these women. Two of the women made the decision to have surgery almost as part of the decision to have testing for the familial BRCA mutation, indicating that they had planned to have surgery if the genetic test showed that they carried the mutation.

...right from the beginning I always knew that I would have it, the prophylactic mastectomy [16].

In comparison, two other women had planned to have a risk reducing salpingo-oophorectomy if they carried the familial BRCA mutation but had not initially planned to have a risk reducing bilateral mastectomy. One of the women describes taking about a year to think the decision through and the other woman notes that she started to become obsessed with the chance of developing breast cancer in the months after her salpingo-oophorectomy.

I was completely obsessed about it; I couldn’t stop examining my breasts. I hated them. I was starting to think these things are going to kill me I don’t want them... [29].

One woman who had had breast cancer was considering a contra-lateral mastectomy but was reluctant to have further major surgery. At the same time she did not want to have another breast cancer diagnosis that might involve surgery to her lymph nodes. She is one of several women who talk about liking their breasts and yet she was giving serious consideration to the possibility of surgery to remove her healthy breast. When recalling her diagnosis of breast cancer, she said:

I was very devastated at getting the news I was going to lose a breast because my breasts were my favourite part of my body [9].

8.3.1 The role of breasts in the construction and maintenance of a feminine identity

“For many women, if not all, breasts are an important component of body self-image; a woman may love them or dislike them, but she is rarely neutral” (Young, 1998, p. 125). A number of the women interviewed for this study indicated the importance of their
breasts to their image of themselves. The woman quoted above talked about the sense of loss she experienced at the time of diagnosis and the subsequent adjustment to her postsurgical body in the months that followed. As the quotations that open this discussion indicate, a number of women like their breasts and these feelings may be instrumental in the decision to have surveillance rather than surgery.

Iris Young (1998) writes about the importance of women’s bodies to our feelings of identity and self worth. Women live within our bodies, experiencing our lives, our pleasure and pain within our physical body. While the look of a woman’s breasts may be viewed as most important in patriarchal societies, Young (1998) suggests that what matters most to women are actually the feelings in our breasts, rather than the look. These feelings may be strongest at moments in a woman’s life when the reproductive capacities of her body are most obvious to her, for example when she is newly pregnant and when she is breast feeding her baby. Women with an increased risk of developing breast cancer have to balance their concern about developing cancer with the potential changes to their identity, their feelings of femininity, of womanliness, in making decisions about risk reducing surgery.

One of the women planning to have a risk reducing mastectomy was clearly exploring her ideas about self image and considering her options in terms of reconstruction. She competes in Iron Women competitions, wearing lycra and keeping her hair short. She considered the possibility of not having a reconstruction but her husband was clearly concerned about this, telling her that people would look.

...you know there’s option of not having anything done after, just being flat. I mean he said to me no that this wouldn’t be an option because he said you know because of all the sport we do and the lycra that we wear and things, he said it would be – and I normally have my hair really short and he said you know people would look [27].

Societal understandings and expectations contribute to ideas about what male and female bodies should look like, and how males and females should behave. Gender identity becomes, at some levels, a “body performance” with deeply entrenched societal expectations regarding sex-specific non-verbal behaviours including norms for body movement, eye contact, allowances for personal space and appropriate facial
expressions (DeFrancisco & Palczewski, 2007). Women experience significant cultural pressure to conform to the norms defining attractiveness and female beauty (DeFrancisco & Palczewski, 2007), which for the husband mentioned above included the need for his wife to have breasts as a visible sign of her gender. While the comment appears to be primarily concerned with the effect on his wife, there is also the possibility that being associated with a partner who is visibly androgynous may threaten a man’s heterosexual identity. Women who refuse to conform to the prevailing expectations may face discrimination and harassment simply for declining to “buy into” societies expectations regarding female beauty, as indicated by his concern that people would look at her if she competed in a women’s competition with short hair and no breasts.

Croster and Boehmke (2009) completed a review of survivorship considerations among BRCA gene mutation carriers. They found that many women choose to have surveillance for breast cancer rather than risk reducing mastectomy. There appear to be several reasons for this trend including breast surveillance offering a better chance of early detection (when compared with surveillance for ovarian cancer), the surgery being more complicated than salpingo-oophorectomy, and the influence of the value that society places on breasts as symbols of femininity, sexuality and attractiveness.

Women who have risk reducing mastectomy are generally comfortable with their decision and with the reduced worry after the surgery (Croster & Boehmke, 2009; Kenen et al, 2007; Lloyd et al, 2000). However, they do report finding the surgery and adjustment more difficult than expected (Lloyd et al, 2000). As discussed in chapter six, women in the current study reported problems with healing after the surgery, and with the positioning and feel of their reconstructed breasts. Other studies have also found that women are unhappy with their body image after surgery, and find the impact of the loss of sensation in their breasts difficult to adjust to (Lloyd et al, 2000; Kenen et al, 2007).

8.3.2 The role of breast reconstruction in maintaining a feminine identity

Breasts are a visible, tangible signifier of womanliness, a symbol of feminine sexuality. As with the women interviewed by Nina Hallowell (2000), all the women in this study indicated that breasts were an important part of their femininity and their identity as
women. In New Zealand, publicly funded breast reconstruction was available at the same time as the mastectomy for these women, followed by nipple reconstruction and tattooing of the areola. All the women were availing themselves of at least the initial reconstruction. They were divided on whether they would proceed with the nipple reconstruction, with one woman saying that she probably would not go ahead with nipple reconstruction because reconstructed nipples *don’t react like a normal nipple would, they’re hard little lumps...* [30]. A woman who competed in sporting events was encouraged to have a reconstruction by her husband. He also encouraged her to have a nipple reconstruction:

...*then he said well I think you should also consider having the reconstruction of the areola and nipple it’s up to you. But certainly because he said every time you just catch yourself in the mirror it will be a shock because it’s different, but if something’s there it won’t be quite such a mental, such a you know a feature* [27].

For other women, having breasts that looked as much like “real” breasts as possible was important:

*I still have to look at myself in the mirror every day and I want something that’s not just going to fill my bra, I want something that I can look at and not burst into tears every day*[29].

The power of nipple reconstruction and tattooing of the areola in creating reconstructed breasts that look “normal” was recently demonstrated by photos in a presentation given by a Christchurch plastic and reconstructive surgeon (Simcock, J, 2010). The “before and after” photographs he showed illustrated the way in which attention was drawn to the nipple-areola complex rather than to the scars that cross the breast after a mastectomy.

The power of the normalising look is significant in our society, with it being extremely unusual for a woman who has had a unilateral mastectomy not to wear prosthesis or have a reconstruction, or for a woman to have a bilateral mastectomy without a reconstruction (Broom, 2001; Young, 1990). While the “look” was currently foremost in their thinking for most of the women interviewed for this study, there are indications that the “feel” is as important, or perhaps more important for some women. One of the
women in this study alludes to this when she says my breasts feel kind of like rocks and describes her reconstructed breasts as sitting very high on her chest. She later says that post-surgery there is no specialness or modesty about that area any more [16]. Another woman talks about making contact with a woman who had a risk reducing mastectomy several years ago.

*I mean dressed you wouldn’t know and so to see and touch, it was good* [10].

This woman allowed the respondent to look at and touch her reconstructed breasts. For the respondent, this experience was very important in her decision not to undergo mastectomy. She explained that the woman looked normal when she was clothed, but that the breasts did not feel ordinary, they felt firm rather than soft.

Young (1990) reports that many women are surprised and disappointed by both the look and the feel of reconstructed breasts, because they no longer feel like their own breasts. Several studies have reported that women find that their reconstructed breasts feel unnatural to touch or do not feel like their own after risk reducing mastectomy (Bresser et al, 2006; Hallowell, 2000; Hopwood et al, 2000; Kenen et al, 2007). A woman in the study by Kenen et al (2007) reported that she had changed her behaviour and no longer hugged people as much because her breasts felt hard and uncomfortable. Alterations in hugging and touching behaviour were also reported by two women who had undergone risk reducing mastectomy in Hallowell’s (2000) study.

### 8.3.3 Losses associated with mastectomy

Many women having a mastectomy after a diagnosis of breast cancer experience considerable distress at the loss of their breast. One young woman interviewed for this study said:

*I couldn’t talk about it prior you know to the surgery when we talked about it I’d just burst into tears and really I mean because I liked my breasts...* [9].

Another woman commented that her partner was more concerned about the possibility that she would have surgery to remove her breasts:
Reconstruction “hides” the loss that a woman experiences when she has one or both breasts removed. The loss includes the loss of feeling and sensitivity, not just sexual feelings, but the feeling of being a woman in the world with breasts (Young, 1990). Two women interviewed by Hallowell (2000) reported finding it difficult to get used to their altered body shape and feel after mastectomy and reconstruction. While they looked “normal” their reconstructed breasts felt unnatural, much like the woman discussed above.

Breasts are a central element of a woman’s image of her body, a source of sexual pleasure and bodily pride, and an important aspect of her identity, so it is unsurprising that the loss of a breast is distressing (Young, 1990; Young, 1998). Western medicine tends to objectify the body seeing it as a collection of parts, and medicine is strongly oriented towards active interventions aimed at “fixing” the part that is “broken” (Young, 1990; Broom, 1995). In this model, breasts are considered to be dispensable. At a societal level, many people consider breasts to be decorative rather than functional (Young, 1990). As one of the women who had a risk reducing mastectomy said:

...you don’t need them for anything specific and it’s not something you need I mean they’re sort of extra things [24].

In writing about her own diagnosis of breast cancer, Broom (2001) notes that very little is said about mastectomy involving the loss of a site of sexual or erotic pleasure for a woman. The comment that breasts are extra things and are not needed for anything specific suggests that sexual pleasure is also something “extra” rather than a fundamental aspect of every individual. As this discussion indicates, there are very real losses associated with mastectomy.

8.3.4 The dichotomy of retaining youthful reconstructed breasts after salpingo-oophorectomy

There is an interesting dichotomy for a woman with a BRCA mutation who decides to manage her risk by having surgery. As indicated, women in New Zealand are offered a
reconstruction at the same time as a risk reducing mastectomy. One of the women, aged in her late thirties, talks about how, post-surgery, she has these high, hard reconstructed breasts, quite unlike her own breasts. The words she uses to describe her reconstructed breasts are similar to the language used to describe a younger woman’s breasts. Another woman, who has had breast cancer, talks about the possibility of delaying a reconstruction until her late forties and getting the contra-lateral breast lifted so that she’ll have nice great breasts in her fifties. These ideas suggest that mastectomy with reconstruction includes the possibility of retaining youthful looking breasts, breasts that are high and firm, breasts that do not sag in the way described by postmenopausal women in Dillaway’s (2005a) study. At the same time, these women are also considering or undergoing risk reducing salpingo-oophorectomy and experiencing menopause some years earlier than they would otherwise. The woman who was thinking about how to have nice breasts in her fifties also commented on the effects of menopause on skin elasticity and bone health, describing the effects of the aging process even as she considered the possibility of keeping her chest looking like that of a younger woman.

8.4 Women’s language

Absolutely they’ve got the potential to kill me. As soon as they went, as far as I am concerned... I had my family, get rid of them. I don’t want them [29].

...oh well I didn’t think I would really miss them... [4].

I mean they’re useless to me anyway. They’ve never been any good to me...my ovaries haven’t really ever worked properly [19].

The language used by the women, and the language that they report the medical professionals as using, is striking. The women who have had risk reducing salpingo-oophorectomy all talk about the desire to have their ovaries removed, regardless of their age. Their language suggests that some of the women experienced a sense of urgency to have the surgery done in order to reduce the risk. The language they use as they discuss having their ovaries removed is evocative, with ovaries frequently referred to as those things and phrases such as get rid of dominating the language used by several women.
One woman said that her ovaries were probably ready to *clap out* [1] as she approached menopause. Another woman describes feeling *rapt* when she was able to have surgery within six weeks of seeing the gynaecologist. Their choice of words suggests that they viewed their ovaries as a site of potential risk and that the danger posed by this risk can be managed or controlled by removing the site of risk. The language the women used during the interviews suggests a process of separating themselves from the site of danger mentally, prior to the physical separation brought about by the surgery.

Their language is suggestive of an emotional distancing, perhaps because they perceive their ovaries as dangerous, as a site for cancer. Nina Hallowell (2000) takes the position that genetic risks constitute corporeal (internalized, of the body) or embodied risks and may therefore be less easily avoided than external risks. Corporeal risks are potentially threatening to the self. Hallowell describes a process of Cartesian splitting of the body and the self so that the body is constructed as “other” or not of the self. Body parts may have differing levels of significance to self identity, for example hidden body parts may be easier to objectify. The language used by the women interviewed for this study may be a means of objectifying body parts that are perceived as dangerous. The use of language that objectifies body parts and makes them “other” may be an important part of the process that allows the women to make a decision to have risk reducing surgery.

The ability to objectify body parts, particularly hidden ones such as ovaries appears to change with time so that it is easier to make ovaries “other” as a woman approaches the age at which menopause might naturally occur. A number of women in this study had undergone salpingo-oophorectomy when they were peri- or postmenopausal. In comparison with the use of terms such as *useless*, *those things* and *get rid of* used by premenopausal women, older women describe not really *missing* their ovaries and thinking that they didn’t really *need* them anymore. Their language use suggests a decision that is, understandably, less complex than for younger women. The language used by the women who had had, or were planning to have, premenopausal salpingo-oophorectomy indicates a more active process of objectification and distancing.

Two of the women who have had risk reducing mastectomies demonstrate a similar propensity to objectify their breasts and make them “other”, perhaps as part of their rationalisation regarding the surgery:
...they weren’t that attractive anyway after breastfeeding our three children... All for the sake of a couple of boobs that are pretty much unattractive anyway [19].

...you don’t need them for anything specific and it’s not something you need I mean they’re sort of extra things... my post-children’s body wasn’t quite what I would have liked it to be in any case, my breasts had gotten huge after I had kids and I really hated that. So I didn’t feel, I missed the breasts I had when I was twenty... [24].

These women describe their pre-mastectomy breasts as unattractive and as sort of extra things suggesting a process of separation from their breasts, which they perceived as time bombs and as being the site of an unacceptably high risk. The decision to manage the risk of breast cancer surgically may be more straight-forward for women who do not ‘like” their breasts as much. Conversely, women who have chosen to have surgery may rationalise their decision by reminding themselves that what they have lost was not particularly attractive or necessary after all.

8.5 The language used by medical professionals

The language the women report medical professionals using when discussing ovaries also deserves consideration. The women who participated in this study had consulted with a number of different gynaecologists, most of whom were male. The language that the gynaecologists use when talking about ovaries is a language of deficit. Male gynaecologists are reported as describing ovaries as little shrivelled up peas [17], and empty petrol cans [12]. A female general practitioner is reported as saying it’s not going to make any difference to you in any way because your ovaries would be just about useless now anyway [11]. The women to whom these remarks were made all reported finding them upsetting and commented that the attitude and words of the medical professionals were sometimes instrumental in delaying their decision to proceed with surgery.

These words speak volumes when considering the identification of this group of women as mothers and the association of their reproductive capacity with their ovaries. Even as women approach menopause, they do not find decisions to have their ovaries removed
easy, with some women reporting a very real sense of loss when they think about no longer being able to have children. It is not that they actively want to have more children; it is the lost potential that they grieve for. For some women menopause is associated with aging, with some young women in Hallowell and Lawton’s (2002) study noting that maintaining a particular type of body was important in order to maintain an identity as a young woman, and suggesting that premenopausal salpingooophorectomy and the subsequent early menopause would result in an aging body. The use of words like empty, useless and shrivelled suggests that medical professionals also associate menopause with aging, and display disregard for organs that have given life to children and youthfulness to these women.

Some research is indicating that attitudes regarding the association between menopause and aging may be starting to change, at least in some sectors of society. In a study of forty-five American women, Heather Dillaway (2005b) found that the women she interviewed regarded menopause and aging as two distinct processes, stating that they did not feel old at the time of menopause (reproductive aging). However these changes in attitude and consequent language use may not have reached the medical profession as yet. Medical textbooks and popular texts use a similar language of deficit to describe the processes that occur in women’s bodies both at the time of menstruation and at menopause (Martin, 1994). Martin (1994) reviewed a number of medical texts and found repeated descriptions of menopause replete with words such as “fail”, “atrophy”, “decline” and “wither”. She suggests that the medical view of menopause is of a failure of an authority structure in the body and that this is coupled with and supported by negative stereotypes of aging women in society. Feminist paradigms conceptualising menopause as a time of natural transition rather than as a disease requiring treatment have gone some way to influencing attitudes towards menopause (Gannon & Ekstrom, 1993). However it is clear from the language reportedly used by these medical practitioners that there is still room for improvement in conceptualising menopause as a natural life transition.

There are inherent power differences in the relationship between a medical professional and a patient, which may be reinforced by the language the doctor chooses to use. Feelings of vulnerability are associated with being at increased risk of developing cancers which predominantly affect women, as illustrated by the quotation that opens this chapter and previously mentioned comments about the degradation of constantly
having to remove one’s top in the breast clinic. Women also report feeling vulnerable regarding the possibility of having their *womanly parts* removed. The experience of having to have multiple breast biopsies has left another woman in this study feeling *vulnerable* each time she attends the breast clinic. Two other women in the current study talk about feelings of vulnerability and dependency that they experienced when they needed help after surgery. The language used by medical practitioners, describing potent, life-giving organs such as ovaries as *empty, useless* and *shrivelled* may contribute to the vulnerability these women are already experiencing and reinforces the power differential inherent in medical consultations.

8.6 The role of husbands and partners in surgical decision making

The women interviewed for this study identify themselves as women in relation to the people around them. Most of the women interviewed had partners and many of these women identified themselves as wives or partners in ways that suggest that this role is also a significant part of their identity. During the interviews a number of women talked about the role that their husbands and partners played in their decisions regarding managing the increased cancer risk. Some husbands and partners had very limited involvement, essentially being asked to support the decision their wife and partner had made, while others attended medical appointments and were actively involved in the decisions. The younger women tended to involve their partners more, perhaps reflecting changing societal expectations and behaviours. Attendance at medical appointments may also reflect the fact that the decisions are likely to have a greater impact on the couple’s relationship when surgery occurs at a younger age. The women perceived their partners as supportive and felt that they had their best interests in mind:

*My partner, nothing but support. He would rather have three quarters of me than see me in a box basically* [30].

*He feels the same as I do, I’d rather be around for another forty years than not* [27].

The influence of male partners is significant in the women’s decision making process. They want their partner to survive and they can live with the results of the surgery if that is what it takes to keep her alive. While the women appear to be responding to the
messages from their partners positively, they may experience considerable, perhaps unintentional, pressure to have surgery to reduce the chance of a cancer diagnosis and to increase the chance of staying alive to be there for their partner, in much the same way as the women indicate that surgery enables them to be there for their children.

The respondents indicated that partners played a more significant role in decisions about risk reducing mastectomy than salpingo-oophorectomy. Some women made comments that suggested that they were experiencing significant pressure to go through with the multiple surgical procedures required for breast reconstruction. As noted above, one woman considered not having a reconstruction but was strongly encouraged to do so by her husband. Several other women commented that their partners were involved in decisions regarding reconstruction and the extent of this. One woman had decided not to have nipple reconstruction, commenting that her cousin had this done more done for her husband than for herself and she said if she had her time over again she wouldn’t do it again [30]. The male preference for breasts is strongly articulated in our society and one could argue that these men, while seeming to have their partner’s best interests in mind, were also thinking about their need to have a partner with breasts.

The outcome of the surgery may be significant for the partners, particularly when their wives and partners experience an early menopause and with it, the potential for loss of libido and pain or discomfort during intercourse. As noted previously, one woman who had lost all interest in her sexual relationship commented it’s a case of working at it if you’re in a relationship [30]. Several women undergoing premenopausal salpingo-oophorectomy reported that nobody explored the possibility of an alteration in libido and sexual response with them. If women are undergoing surgery unaware of possible alterations in libido and sexual response, it is very likely that the male partners do not have a good understanding of the possible effects of the surgery either.

While most of the women interviewed for this study were in heterosexual relationships, two of the women interviewed were lesbians. The numbers are too small to draw any conclusions regarding the experience of partner influence and support, but the voices of these women deserve to be heard alongside their heterosexual counterparts. One of these women recalled that as she was making treatment decisions after she was diagnosed with breast cancer, she was thinking about
...some of these things that I was going forward and the decisions that I was making wasn’t necessarily when I was thinking about myself, it wasn’t necessarily thinking about just me. It was thinking about me in a relationship at the same time or thinking about myself in future relationships... [25].

Her comments suggest that breasts are important for women in a relationship with another woman, just as they appear to be important for women in heterosexual relationships. She goes on to talk about the extremely limited information she was able to access for lesbians with breast cancer and their partners, indicating that there is probably also very limited information specifically for lesbian women from hereditary breast and ovarian cancer families. Her comment also illustrates the way in which women consider others, in this case their partners, when they are making decisions about surgery.

While there is recognition that hereditary breast and ovarian cancer impacts the wider family, few studies have examined the impact on the partners of women who have an increased risk of breast and ovarian cancer. Metcalfe and colleagues (2002) conducted a questionnaire survey of fifty-nine spouses of BRCA mutation carriers and found that a small number of spouses (14%) felt that they needed additional information regarding the implications of the BRCA mutation for their partner. Additional support needs were identified by 18% of men aged less than fifty years and by 6.7% of older spouses. The men surveyed by Metcalfe et al (2002) reported that the fear of losing their partner to cancer was their greatest concern. This finding is reflected in the reports of the women in this study who say that their partner supported their decision to have risk reducing surgery because they would rather they were alive.

8.7 Risk reducing surgery and the impact on women’s friendships and support networks

Women’s friendships are often very significant in their lives. In a study of young mothers with cancer, Elmberger et al (2008) report on the importance of feeling connected to friends who understood and to other women in similar situations. The question of whether or not to tell friends and family about the decision to undergo
surgery was discussed by all the women in this study. Several women reported adverse reactions to their decisions about surgery among both friends and extended family. A number of women talked about their experiences of telling friends about their increased cancer risk and the different responses they received, with some reporting that their friends have found their choices difficult to understand. Some women chose not to tell very many people and reported feelings of isolation and separation from their friends.

Young women choosing to have their ovaries removed in their late thirties and early forties face the possibility that they will fall “out of step” with their peers, with the friends whose friendship may have sustained them through other life-changing events including the birth of their children. By precipitating menopause some years before they would normally expect it to occur, they may face the changes without the support and camaraderie of friends who are also experiencing these changes. In a pilot study regarding women’s understanding of menopause, Gail Darke (1996) noted that women tended to discuss menopause with their friends rather than with family members. If one’s friends are not yet experiencing menopause, the possibility of being “out of step” with their peers may result in a sense of social isolation for women who have had a premenopausal salpingo-oophorectomy.

Some women chose not to tell very many people what they decided about risk reducing surgery and women who experienced negative reactions then chose not to discuss their choices with other friends or family. One woman describes having had a lot of negativity from her family, saying that they call it mutilation [27]. Another woman explains that her sister emailed me and said why are you doing this? It’s so drastic [29]. While she has been able to resolve the different perspective with her sister, she also reports a lack of support, or indeed contact, from two women who she had thought were her closest friends. A woman may decide that she only wants a few people to know about her decision to have surgery and then have this decision taken out of her hands, as was the case for a woman who kept pretty quiet and my father-in-law was very naughty and told quite a few people after I had said I didn’t want anyone knowing [19]. Later, she met people who were not “supposed” to know but who she felt were looking at her and thinking about her having had her breasts removed. For one woman, the decision to have genetic testing and then surgery was intensely personal with very few people outside her immediate family knowing what she was going through. She explained that the result of this was that she was living a kind of double life and having to tell white
lies to explain herself during the recovery period. Only one woman reports receiving total support from her extended family and she acknowledges the role her sister’s recent diagnosis of breast cancer may have played in their response.

The negative reactions or the choice not to tell people about the surgery contributed to the isolation these women experienced as a result of being at increased cancer risk. In an exploratory study involving focus groups of women with BRCA mutations, Regina Kenen and colleagues (2006) found that feelings of isolation and “social separation” (emotional distancing) were prevalent. Matloff and colleagues (2009) report anecdotal experience with women who have had negative reactions when telling friends about their BRCA status and surgical choices, further contributing to feelings of isolation. Given the significant risk these women face and the surgery they may choose to undergo to manage this risk, it is concerning that so many women report experiencing feelings of isolation. Contact with other women from families with hereditary breast and ovarian cancer, either face to face or through internet support groups such as the FORCE website and the recently formed New Zealand group called The Gift of Knowledge may help to ease the sense of isolation. Genetic counsellors are also in an ideal position to make enquiries regarding a woman’s sources of support and to facilitate contact with other women in similar situations.

8.8 Conclusion

In this chapter I have explored the experience of managing an increased risk of ovarian and breast cancer through removal of womanly parts, namely a woman’s ovaries and breasts. Ovaries function to produce the hormones that stimulate the development of secondary sexual characteristics at puberty. For many years they maintain the menstrual cycle that is central to a woman’s reproductive capacity. Women with an increased risk of ovarian cancer face a complex dichotomy, one in which the organs that are central to fulfilment of their reproductive potential, to becoming a mother, also hold the seeds to their demise. The women in this study identified strongly as mothers and expressed a need to stay alive, to be there for their children. In order to fulfil this responsibility, many of them chose to have their ovaries removed. The surgery and resulting early menopause brought challenges to their identity as women.
Previous studies have suggested that salpingo-oophorectomy alters the way a woman feels about her body, rather than altering the way her body looks. One woman in this study commented that removal of her ovaries and uterus would not matter because they are not seen. However, a number of women in this study and in the study by Hallowell (1998) describe changes to the way that their bodies look after salpingo-oophorectomy. These changes include weight gain and altered body shape. In addition, a woman in this study comments on her fear that her male partner no longer finds her feminine and another woman indicates that she would need to use hormone replacement therapy to stop her from becoming a man. These observations suggest that salpingo-oophorectomy not only alters the way a woman feels about her body, it also has the potential to alter the way her body looks. Given societal pressures to conform to certain norms of feminine attractiveness, and the observation that being desirable to men is intrinsic to the sense of self for many women, premenopausal salpingo-oophorectomy is a complex “choice” for many women.

Risk reducing mastectomy is an equally challenging “choice”. Breasts are a central aspect of femininity in many Western cultures and are often “displayed as part of women’s appearance work…” (Stearn, 1999, p. 309). Women who have had a mastectomy after a breast cancer diagnosis almost always disguise the loss of a breast by having reconstructive surgery or wearing a prosthesis. The prevalence of reconstructive surgery in women having risk reducing mastectomies and the discomfort for the partner described by one woman who considered not having a reconstruction highlight the importance of the look of a woman’s breasts. However, reconstruction may bring its own problems in that the reconstructed breasts may look normal but do not feel like the woman’s breast felt prior to surgery.

The findings of this New Zealand study indicate that women with an increased risk of ovarian and breast cancer are prepared to undergo surgery to “get on with” the rest of their lives and to be there for their children. The decisions regarding surgery are complex and women often lack adequate information and support before and after the surgery. Despite the challenges, the majority of these women were comfortable with their decisions and view the decision to proceed with surgery as necessary.
Chapter Nine

“Getting on with it” in a risky world

In this thesis I have used narratives obtained through qualitative semi-structured interviews to explore the experiences of a group of thirty-two Pakeha New Zealand women who are living with an increased risk of developing ovarian cancer. The majority of the women also have an increased risk of developing breast cancer, and a few women have increased risks for cancers associated with Lynch syndrome, in particular colorectal and endometrial cancer.

The chance of developing cancer is estimated to be high for these women. Research indicates that women with an identifiable mutation in BRCA1 or BRCA2 have up to a 40% chance of developing ovarian cancer and up to an 85% chance of developing breast cancer (Antoniou et al, 2003; Chen et al, 2006; Suthers, 2007). These risks are significant, particularly when compared with the population chance of developing these cancers, less than a 2% risk of ovarian cancer and about a 10% risk for breast cancer. The options for medical management of the risks are limited. Women may choose to have intensive surveillance aimed at the early detection of cancer or they may choose to reduce the chance of developing cancer by having surgery to remove the site of the risk.

The serous ovarian cancers that tend to develop in women who carry BRCA mutations are aggressive. Surveillance utilising regular CA125 measurements and ultrasound examinations has proven ineffective in detecting these cancers at an early stage when a cure may still be possible (Cannistra, 2004). For this reason, international medical recommendations suggest that women who have an inherited risk of developing ovarian cancer should have their ovaries removed when they have completed their families, and preferably by age forty (Daly et al, 2010; Domchek et al, 2010; Haber, 2002). Premenopausal salpingo-oophorectomy has been shown to reduce the risk of both ovarian and breast cancer (Domchek et al, 2010; Kauff et al, 2002; Rebbeck et al, 1999). But premenopausal salpingo-oophorectomy comes with a significant side-effect, which is that of a surgical menopause often ten or more years before these women would reasonably have expected to reach menopause if there had not been intervention. The majority of the women in this study had, or were planning to have, risk reducing
salpingo-oophorectomy.

Surveillance of breast tissue using annual mammography and magnetic resonance imaging (MRI), along with six monthly clinical breast examinations, is reasonably effective in detecting breast cancers at an early stage when treatment is likely to be successful (NICE guidelines, 2006; Saslow et al, 2007). However, women who opt for surveillance live with the knowledge that they are very likely to develop breast cancer one day. Risk reducing bilateral mastectomy is also offered to these women as this very substantially reduces the chance of developing breast cancer (Domchek et al, 2010; Evans et al, 2009; Hartman et al, 2001; Meijers-Heijboer et al, 2001). A few of the women interviewed for this study had chosen to undergo risk reducing mastectomy, preferring this option to the fear and anxiety that accompanied life with breasts that were likely to develop cancer one day.

This study is the first to explore and report the experience of living with an increased risk of ovarian and breast cancer for Pakeha New Zealand women. The development of the study drew on similar studies conducted in the United Kingdom, Canada and Australia (D’Agincourt-Canning, 2006; Hallowell et al, 2002; Hallowell et al, 2004; Kenen et al, 2003; Lim et al, 2004; Meiser et al, 2000) and on my clinical experience working as a genetic counsellor with New Zealand women undergoing risk assessment and genetic testing for hereditary cancer syndromes. During the course of the project the literature exploring the experiences of American women has also been examined (Babb et al, 2002; Kenen et al, 2007). This combination of knowledge from the international literature and from daily interactions in the workplace suggested that New Zealand women were likely to manage their risk in similar ways to their overseas counterparts. However, New Zealand has its own unique social, cultural, and political history and therefore it was important to begin to understand these unique influences in relation to the way that these women experience and live with their risk. Furthering this understanding is important in terms of the implications for clinical practice for health practitioners such as gynaecologists, oncologists, breast and plastic surgeons, genetic counsellors, nurses and psychologists. The findings of this study contribute both to the ways in which individual health practitioners understand and work with people with inherited cancer syndromes, and to service planning and development. Areas for further research are also identified.
How do these women approach life with the knowledge that they are likely to develop cancer one day, unless they undergo surgery to reduce that risk? What is it like to have healthy body parts removed? Body parts that are central to the identity of these and indeed of all women. The majority of the women who participated in the interviews for this study are very clear that the way they approach their risk is to “get on with it”. They use their desire to survive in order to be there to fulfil their responsibilities as mothers, partners, daughters, sisters, friends and colleagues to motivate them to undergo surgery to have their ovaries and sometimes their breasts removed. Over and over again, they can be heard saying that they just got on with it; they just got on and did it.

9.1 “Getting on with it”: A New Zealand way?

“Getting on with it” has emerged as a dominant theme in the narratives of the women who participated in this project, as the way in which the majority of these women are approaching their risk. I suggest that “getting on with it” is a deeply entrenched social, cultural and gendered expectation in New Zealand. An expectation that is so entrenched as to go unnoticed. New Zealanders, with our history as a nation of peoples who made long and dangerous voyages first from Polynesia and, much later, from the United Kingdom, to settle these islands, appear to think that “getting on with it” is just what we do. More recently, we built on those early pioneering views about courage and strength in the face of challenge, when we became part of a massive “social experiment” during the 1980’s, when neo-liberal government was introduced (Kelsey, 1997). Neo-liberal governance holds at its heart ideas about individual responsibility, local and individual autonomy, with governance from a distance (Petersen, 1998; Petersen, 1999). The goal of neo-liberal governance is to create individuals who function autonomously, governing themselves and managing their own risks. During the period that neo-liberal policies were introduced, the New Zealand health care system underwent a series of rapid reforms (Gauld, 2003). The influence of neo-liberal policies, along with global changes in thinking regarding paternalism in medicine, has resulted in a health care system with a significant emphasis on individual autonomy and responsibility.

The women in this study, many of whom grew up with the introduction of neo-liberal politics in New Zealand, appear to be living out dominant expectations that New
Zealanders will each take responsibility for their own health and well-being. They are prepared to undergo significant, life-altering and potentially disfiguring surgery in order to fulfil their responsibilities to be there to care for their families.

The expectation that individuals are responsible for managing themselves and their relationship to risk is common throughout much of the Western world. Beck (1992) used the term “risk society” to describe the organisation of societies in response to risk as a socially constructed phenomenon. The concept of risk has always existed, but what has changed in the contemporary era are the social conditions within which risk is present (Austen, 2009).

Genetic counselling has developed during the same period as both the rise in theorising about risk and the rise in neo-liberal thought and politics. At the same time, technological advances have resulted in a rapidly advancing understanding of genes and their contribution to disease. The ability to enumerate the possibility that a given individual will develop certain types of cancer now exists for some families. Much of the discourse of the genetic clinic is about risk and options for managing risk. There appears to be an implicit understanding underlying the practice of clinical genetics which holds that attending genetic counselling is the first step in taking responsibility for, and indeed managing, one’s genetic risk (Koch and Svendsen, 2005). Beck (1992) conceptualises risk as something negative, to be avoided or managed in some way. This negative conceptualisation of risk is being challenged with writers such as Austen (2009) and Horlick-Jones and Prades (2009) questioning the empirical basis of Beck’s theory and suggesting that research exploring individuals’ lived experiences of risk is needed in order to underpin theorising about risk. Their questions are supported by the findings of this study, in which the majority of the women demonstrated a primarily positive and optimistic approach to the increased chance of developing cancer. Indeed, many of these women demonstrated a life-affirming use of a specific piece of risk information. Their choices support Horlick-Jones and Prades (2009) observation that diverse responses to risk are observed in the real world and challenge the negative connotations that accompany the conceptualisation of risk in Beck’s writing.

While the majority of the women in this study present a narrative of “getting on with it”, these same women indicate that there is often an initial period of distress and disorientation on learning about the increased risk. Clarke (2009) describes this initial
distress as common among people living with chronic medical conditions and the accompanying risk. Indeed, emotions and intuition appear to be a part of decision making in response to uncertainty (Zinn, 2008). The immediacy of emotional response can be clearly seen in one of the interviews in particular:

I believe in the power of positive thinking. And my sister in [name of town] who had the test the same day as me, she had convinced herself she was positive and she rang me and she said no. I said oh. And I thought holy crap if you’re not then there’s a chance that I am. Now the big, big mistake about that day was and I don’t know whether [Genetic Counsellor] said to me when you go and get your results take a support person. I don’t know whether she said that or not but I didn’t take anyone, I went by myself. I got my results. I was an absolute cot case and I couldn’t drive myself home. I had to spend the day in [name of town] because I hadn’t got myself together enough to drive home… So my GP her response really shocked me, because as soon as she got the results I said I’m not getting my breasts off and she was shocked. She said but you’ve got an 85% chance of getting breast cancer. She was shocked that I was not considering that surgery but by the time I got home that day I’d talked to a friend of mine about it and talked to her about it and by the time I got home I said to my husband, I think I’m going to consider having the breast surgery. [29].

This woman describes an overwhelming response to receiving a positive BRCA predictive test, resulting in a decision on the drive home, to have a bilateral risk reducing mastectomy, even though she had been sure prior to the appointment to discuss the result that she would not consider this surgery. While the surgery did not occur for some months, the initial emotional response to the test result was instrumental in her decision making. Clarke (2009) goes on to describe a counter-narrative of hope for the future which is clearly articulated by many of the women in this study alongside a narrative in which the knowledge of the increased risk has literally saved my life [7].
9.2 “Getting on with it”: Gendered expectations

“Getting on with it” in the context of using risk information to motivate risk management decisions suggests that these women have a strong orientation towards the future. The reasons for this future orientation are clear in the statements of many of the women who tell us that they want to be there for their children, to watch them grow up. Their role and identity as mothers is particularly strong in their narratives. Women state that they want to stay alive in order to be there for their children. They also want to avoid their children experiencing the diagnosis and treatment of a serious illness in their mother. Many of the participants described their own experiences of watching their mother go through treatment for cancer and sometimes her death. The findings of this study suggest a strong association between mothering and “getting on with it”. They reflect a socially constructed notion of gender and femininity in which mothering is a dominant role for women.

Connell (2000) suggests that everyday life is organised around the reproductive arena. Women have the reproductive ability to give birth and to feed infants, so it follows that they should take on these tasks and the accompanying responsibilities of caring for the home. Perhaps as part of this role, women in Western societies often appear to take responsibility for the family’s health (D’Agincourt-Canning, 2001), with Richards (1996) observing that women often take responsibility for seeking and disseminating genetic information that will benefit the health of their family. As is the case with many Western cultures, New Zealand women are socialised into caring and nurturing roles from a very early age, learning to put the needs of others, in particular their children and partners before themselves.

Living with an increased risk of ovarian cancer, which is unique to women, and breast cancer which is predominantly a disease of women, and the risk management options available to these women, brings into stark relief the way in which motherhood and sexuality are entwined. Risk reducing salpingo-oophorectomy results both in the loss of reproductive potential and, if hormone replacement therapy is not used, in menopause and the accompanying bodily changes. Risk reducing mastectomy results in the loss of body parts that are visible signifiers of femininity, a part of a woman’s sexual self, and a source of nurturance for her infants. The participants in this study appear to privilege the role of mother, with its socially accepted associations with femininity and womanly
identity, in response to the loss of other aspects of themselves that have previously had a role in their feminine identity.

Biomedical and feminist models of menopause both focus on the changes that occur during this period of a woman’s life. In contrast to feminist research suggesting that many women understand the changes that occur at menopause in either a neutral or positive light (Dillaway, 2005a; Winterich & Umberson, 1999), biomedical models tend to focus on the negative aspects of bodily change at menopause, further compounding understandings of women’s bodies as deviant when compared with men’s bodies (Gannon & Ekstrom, 1993). Biomedical models tend to be privileged as a result of both dominant thinking regarding medicine and media portrayals of women at the time of menopause, resulting in societal constructions of menopause as a time of negative bodily change. This model equates “womanhood” and femininity with fertility, reproductive potential, youthfulness and visibility. Menopause is therefore seen as a change from having a body that is gendered and feminine, to having a body that is androgynous, old and socially and sexually undesirable.

Individual women often report positive aspects to life at the time of menopause however, both Dillaway (2005a) and Winterich and Umberson (1999) found that many women in their studies were affected by dominant social discourses of negativity and loss, constructing bodily changes such as weight gain, reduced skin elasticity and increased hair growth as problematic. While much of the research regarding women’s experiences of menopause has emerged out of North America, it is likely that New Zealand women have been similarly influenced by cultural and social constructions of menopause emerging out of biomedical paradigms as a time of negative bodily change. Several women in the current study viewed changes such as weight gain after premenopausal salpingo-oophorectomy negatively and raised concerns about whether their partners continued to find them desirable and attractive.

The emphasis on the importance of the role of mother in the current study indicates that some women may turn to a socially recognised and accepted feminine role, that of mother, as a way of justifying and adjusting to the surgery and the accompanying bodily changes. Privileging a role that is uniquely female and widely recognised, albeit in differing ways, may help these women to maintain their feminine identity and sense of womanliness after the removal of body parts that are both visible and tangible signifiers.
of femininity. The presence of children symbolises reproductive potential and past fertility, with the voicing of a desire and need to remain alive to care for children constructed as socially responsible. The presence of children also confers assumptions of heterosexuality. Indeed, being prepared to undergo the removal of healthy body parts in order to reduce risk and remain alive to fulfil role expectations provides a symbolic and gendered representation of women as carers and nurturers.

9.3 Information about risk management options and the implications of risk reducing surgery

One of the most significant findings from this study for clinical practice in New Zealand is the finding that women in this study would like to receive more information from health practitioners. This finding is not new. A number of previous studies have shown that women with a family history of cancer would like to receive more information, particularly about the effects of risk reducing surgery (Babb et al, 2002; Bresser et al, 2006; Hallowell et al, 2004; Klitzman & Chung, 2009; Matloff et al, 2009; Meiser et al, 2000). The women in the current study reported that they would like more detailed information about their options for risk management and about the implications of the different options. This observation may in part be because women’s expectations regarding the provision of information and explanations from health professionals are changing with time. However this finding may also indicate that the results of earlier studies have not resulted in significant changes to the information that is provided to women with a family history of cancer by health practitioners.

Some women report difficulties with having any of their questions answered. The following excerpt describes a woman’s attempts to ask questions about her recovery after bilateral risk reducing mastectomies:

And there was no one to ask and when we had that little thing the last day I was in the hospital, the second last day, the last day he had his whole team with him and he came round and he stopped outside the door of my room and told the team off just sat there and gave this blistering thing that said I am God. I am the surgeon. I am the one in charge here. If you have a question you come to me. You do not
speculate with the patients, if the patients ask you questions you come to me and ask and I will give the answer... So it was very uncomfortable and the team came in and a couple of them just looked like they’d been beaten about the face which wasn’t very pleasant for all of us. So of course then when I had questions at the appointment I think they managed to locate a junior registrar and so I wasn’t going to ask any questions because I didn’t want to get her in trouble. I actually made an appointment, I came home and phoned and said look I actually want to see a doctor because I have questions and I have the right to have them answered. So with great reluctance, the receptionists are wonderful gatekeepers. However they made me an appointment with him and he came in and said how did it feel and I said good. He said it looks good and started to walk out and I said excuse me and he came back in and I asked him the question and he started to leave. He literally would finish answering and start to walk away and I said excuse me four times I held him back in the room...

The limitations associated with lack of adequate information appear to arise out of at least two sources; awareness and understanding of bodily function, and resourcing, training and willingness of staff to facilitate these discussions. The findings of this study suggest that some women have limited knowledge about the ways in which their own bodies work. Examples of this include the woman who had not realized for a number of years that the removal of ovaries was different to removal of the uterus at hysterectomy and would result in menopause, and the postmenopausal woman who thought that she would need to take hormone replacement therapy if she had a salpingo-oophorectomy. Other studies have also found that some women do not have a good understanding of the way their bodies function (Barker, 1999; Darke, 1996). Coward (1992) suggested that her interviews with women produced evidence that some girls and women were lacking basic information about their own bodies and their sexual responses. This finding clearly reinforces the importance of health practitioners taking time to elicit each individual client’s level of understanding and the specific information needs that the individual has.
Difficulties may arise if health practitioners themselves are not well-informed about sexuality and have not had adequate training in discussing sexuality with clients. Glenda Koutroulis (1990) has shown that medical textbooks often lack explanations of normal sexuality, so doctors and other health practitioners may not receive education about normal sexuality during their training. As discussed in chapter five, while sexuality is an important aspect of life, it is often not acknowledged or addressed in medical care. Oncology nurses have reported feeling uncomfortable and embarrassed about addressing sexuality with cancer patients (Lavin & Hyde, 2006) and Katz (2005) notes reluctance by health professionals to mention sexuality or even initiate a discussion about sexual functioning during and after cancer treatment. Other health practitioners have reported believing that survival is more important to patients than the impact of illness on intimate relationships, sometimes actively avoiding raising the topic (Hordern & Street, 2007). Stead et al (2003) report embarrassment and lack of knowledge and experience as factors inhibiting health practitioners raising the topic of sexuality. Perhaps more importantly, they note that some practitioners state that it is not their responsibility to discuss the effects of treatment on intimate relationships. These studies suggest that there are both dominant structures and expectations in the medical system which prevent or make it difficult for individual health practitioners to discuss sexuality with clients, as well as limitations in training that mean that health practitioners do not feel well-informed enough to raise the topic.

Women vary in their desire for information, as the discussion in chapter five regarding sources of information demonstrated. These women ranged from wanting just enough information to make a decision that they believed was informed through to women who researched their options extensively. It is important that health practitioners are aware of the wide range of information needs that women may have as they negotiate a genetic risk assessment, genetic testing and decision making regarding risk management, and that they tailor their approach to suit each individual. Klitzman and Chung (2009) recommend further research to help clarify the roles of health practitioners, friends, family members and support group communities in assisting with and influencing decision making about cancer risk. While future research is important, the reality is that health practitioners such as genetic counsellors need strategies now to assist the women who will attend their clinics this week.
9.4 Resourcing constraints

In the current economic climate, resourcing for health care is tightly controlled. When health services are stretched, the focus becomes the provision of safe and adequate medical care. There is often little or no attention given to resourcing services well enough to provide time for rapport to be established and discussions about anything beyond routine health care to be covered. In the study by Hordern and Street (2007), health practitioners cited lack of time as an important barrier to addressing matters such as sexuality and the impact of medical interventions on intimate relationships. The development of rapport and trust, both of which take time, are crucial in facilitating a relationship in which women are willing to discuss sexuality and body image.

In addition to adequate training, one of the key ways in which genetic counsellors and other health practitioners could be supported to provide adequate services is through the provision of sufficient time to explore the information needs and concerns of individual clients. Currently, Genetic Services in New Zealand provide a single consultation prior to genetic testing for an inherited cancer predisposition, followed by a letter summarizing the discussion and including an outline of the risk management options. Test results are either discussed by phone or during a second consultation. People who initially receive a positive result by phone are then seen in clinic to review the results and the management options, while those who receive their result in clinic are followed up by phone. The consultations involve discussion of complex, often unfamiliar, information. There is limited time to discuss the more personal implications of risk reducing surgery. In addition, genetic counsellors also do not receive specific training in discussing topics such as body image and sexuality. Those women who are at increased risk are referred to surgeons to discuss management options in more detail, but there is evidence from this study and from the literature (Hordern & Street, 2007; Katz, 2005; Lavin & Hyde, 2006; Lemieux et al, 2004) that, again, topics such as the potential for alterations to body image and sexuality, including sexual response, receive little, if any, attention from surgeons and other medical professionals.

In medicine, the past thirty years has seen a dramatic shift in the numbers of women practicing, with Rosemary Pringle’s (1998) work suggesting that women are valued as
the human face of medicine. She notes how popular women doctors in specialties such as obstetrics and gynaecology are, indicating that some women prefer to see doctors who demonstrate a degree of understanding about their bodies that male doctors often lack. In contrast, the occupation of genetic counselling has been heavily dominated by women since its inception. All the genetic counsellors currently practicing in New Zealand are women, and the majority of those working in Australia are also women. As health practitioners, women bring with them social expectations regarding caring for others and may adopt a practice that is more holistic and concerned with communication, providing the potential for discussions of more intimate topics including sexuality. However, assumptions that female health practitioners will address topics related to intimacy with women simply because they are women should be challenged. The study of oncology nurses by Lavin and Hyde (2006) demonstrates that female health practitioners avoid this topic at times, just as their male colleagues do.

Both the literature and the women who participated in this study indicate that patients are receptive to conversations about sexuality and body image, often desiring confirmation that the changes they are experiencing are normal. However, the literature also highlights the reticence of health practitioners to address these topics, for both personal and structural reasons. Pringle’s (1998) study of women in medicine, and Koutroulis’ (1990) study of medical texts both suggest that behavioural and attitudinal change can occur within medicine, indicating that, with raised awareness, topics such as sexuality may gradually become a part of routine health care.

In writing about women’s experiences of menopause, Darke (1996) comments that the lack of information given to patients by their doctors may be a means by which medical professionals try to preserve their power relationship – through control of the knowledge base. Comments by medical professionals such as *we can manage that* [1] when asked directly about the effects of a surgical menopause may indicate a reluctance to impart information but it is speculation to say that this is directly related to a desire to preserve the power imbalance in the medical setting. It may equally reflect structural issues such as the time pressures experienced in outpatient clinics, a lack of training in adequate communication for medical professionals or a protective approach which is now viewed as paternalistic. Challenges to the traditional, paternalistic approach that has historically dominated medicine began to occur with the women’s movement. Women were encouraged to learn about their own bodies and to reclaim control,
asserting their own autonomy in decision making. The tenets of neo-liberal thought in many ways support the move away from paternalism and towards individual autonomy in medicine, further encouraging individuals to take responsibility for their own well-being.

The evidence suggests that one of the reasons women with a family history of breast and ovarian cancer lack access to adequate information is precisely because they are a small group with quite specific information and support needs. In a geographically isolated country like New Zealand, with a small population and a system of twenty District Health Boards providing care across the country, individual doctors are likely to see only one or a few women with a BRCA mutation over the course of their working lives. They may not be aware of the current management recommendations for this group or the implications for sexuality and body image associated with the medical management options.

Access to counselling and psychological support is available through the New Zealand Cancer Society for women who have a diagnosis of breast or ovarian cancer. In my clinical practice I have met with women who are having risk reducing surgery and have had difficulty accessing counselling through the Cancer Society. One of the women interviewed for this study saw a psychologist privately for several sessions as she made decisions regarding risk reducing salpingo-oophorectomy and mastectomy and reported finding this very helpful. Apart from this woman, the availability of counselling was not an issue that these women addressed in their stories.

Genetic counsellors with an interest in this particular area are well-placed to provide ongoing counselling to these women as they have a detailed knowledge of the issues that are specific to women with an inherited predisposition to cancer. However ongoing consultations are currently not funded and the genetic services have such lengthy waiting lists in some areas that any additional consultations are not possible. In addition, genetic counsellors would require additional training if they were going to appropriately explore matters related to body image and sexuality.
9.5 Improving services: The way forward

Improving health services often appears to be reduced to the key resources of time and money. In an era where medical advances mean that people live longer and want access to more costly health care services, time and money are often both in limited supply. The provision of lengthier or more numerous appointments and the resulting opportunity to talk in more detail about living with an increased cancer risk and the options available for medical management of the risk theoretically require additional funding for clinics, additional staffing and additional training. The challenge is to find ways to offer improved services within current budgetary and time constraints.

The findings from this study suggest that additional services may not be required by all women, and that most women will only require additional services at specific times, for example when receiving test results, making decisions about risk reducing surgery and as they adapt to the effects of the surgery. Studies by Bresser et al (2006), Hopwood et al (2000), Lloyd et al (2000) and Patenaude et al (2008) all clearly stated that risk reducing mastectomy should be offered within the context of a multi-disciplinary team and should include the availability of ongoing psychological support. We are remiss in offering this surgery in New Zealand without any psychosocial support or follow up. However, given societal expectations regarding “getting on with it” in New Zealand, the context within which psychosocial support is offered should be carefully considered. Referral for psychosocial support as part of routine practice for these women might help to ensure that this aspect of care is viewed as routine, rather than as an additional service only for those who are deemed to need it.

9.5.1 Multi-disciplinary familial cancer clinics

The model of care delivered through a multi-disciplinary familial cancer clinic may provide a mechanism to improve services to clients within the limitations afforded by current budgetary constraints and restricted staffing levels. For example, in Wellington there is a monthly combined clinic with a breast surgeon and genetic counsellor for women who have an increased risk of breast cancer. The breast surgeon has simply grouped the women with a family history of breast cancer into one clinic and a genetic counsellor attends to triage new referrals and meet with women who have been assessed
as high risk. Women from other District Health Boards can be referred to this clinic and up to date information regarding their management is then provided to doctors in their own area, providing an informal means of education and up skilling. This clinic provides an opportunity to meet with women each year when they attend for surveillance. While the clinic has not been formally audited, women attending this clinic have indicated that they appreciate ongoing contact with the genetic service and an opportunity to discuss risk management options each year. A combined clinic such as this could be extended to include the gynaecological management as part of the same clinic. The possibility of providing more intensive short term consultation with staff such as genetic counsellors, social workers or counsellors, particularly when women are making decisions about risk reducing surgery exists within the current framework of the clinic. Multi-disciplinary familial cancer clinics are offered elsewhere in Australasia using a similar model. This model has the potential to allow genetic counsellors and other health practitioners with a particular interest in this area to undertake further training, for example in talking about sexuality, and to deliver additional services within the context of an existing multi-disciplinary team.

The multi-disciplinary clinic model offers a possible solution not just to the information needs these women raise, but also to some of the other issues that they have identified. As discussed in chapter six, one of the difficulties for these women is negotiating the hospital system and particularly finding their way back onto the clinic follow up lists if they happen to become lost to the system. This is a particular difficulty for the group of women who struggle to “get on with it”. A robust recall system for a multi-disciplinary clinic would reduce the possibility of women being lost to follow up and annual or six monthly appointments would provide a regular opportunity to ensure that other aspects of their care are in place.

9.5.2 Educational aids

The demand for genetic assessment for familial cancer is growing. Previous research has examined ways in which educational materials such as videotapes (Cull et al, 1998) CD-ROMs (Wang et al, 2005) and decision aids (Metcalfe et al, 2007) may be used to facilitate the process of genetic counselling and potentially reduce the amount of time spent with each individual or family. Both Cull et al (1998) and Wang et al (2005)
developed educational materials that they hypothesised would reduce the amount of time that genetic counsellors and breast surgeons spent with clients being assessed for a family history of breast cancer. The materials were designed to enhance the risk assessment process rather than to replace the need for genetic counselling. Both studies reported a reduction in time spent with the client with no apparent reduction in understanding or satisfaction.

Decision aids are tools developed to assist with decision making by presenting the benefits and harms associated with each option, helping with clarification of individual values and providing guidance (Metcalfe et al, 2007). Metcalfe et al (2007) developed a decision aid for women with BRCA mutations to use when deciding about management options including risk reducing surgery, chemoprevention and surveillance. They found that their tool increased knowledge about each option and reduced decisional conflict levels. Mecalfe et al’s (2007) work suggests that well-developed and tested decision aids may be usefully incorporated into clinical use, perhaps in the multi-disciplinary clinic setting, where discussion could follow the use of the decision aid. Given the suggestion of differing cultural attitudes towards approaching risk indicated by the findings of this study, decision aids and other educational materials developed overseas would need to be piloted with New Zealand women and altered to reflect the appropriate societal and cultural values. Research would be needed to determine the appropriateness of use with Maori and Pacific people and people from other migrant groups in New Zealand.

The majority of participants in this study indicated that they used the internet as part of their search for information and support. Studies have indicated that medical professionals do not regularly suggest using the internet (Roche & Skinner, 2009; Taylor et al, 2001), which seems contradictory when considering that many people report using the internet as an adjunct to the health information provided by their doctors (LaCoursiere et al, 2005; Sillence et al, 2007). The internet is a rich source of information and online support as well as a means for women to find a community of other women who are facing similar decisions. The findings of this study suggest that one way that genetic counsellors and medical professionals could provide additional information and support would be to enquire if the client has internet access and to offer the web addresses of sites that provide accurate, up to date information and online support. Engaging with and using the internet as a source of information and support for
clients means that health practitioners need up to date knowledge about sites to refer clients to. This could be accomplished by selection of only a small number of sites to suggest to clients as a starting point, which could be regularly reviewed by a team member on behalf of the particular health service. Clients often provide valuable insight into web sites that they have found, so the responsibility for finding and reviewing sites could potentially be shared between clients and health care providers.

9.5.3 Group genetic counselling

The possibility of using group sessions for the initial assessment of hereditary breast and ovarian cancer was piloted by Ridge et al (2009). They found that the sessions were efficient in that they could conduct a group session for three or four women in slightly longer than the time required for an individual genetic counselling appointment. The time saving afforded by grouping women was off-set by the need for more extensive follow up after the group session. A comparison of satisfaction with the group session and women seen individually showed similar levels of satisfaction but they noted a number of disadvantages including privacy concerns and the potential for group influence on decision making.

The concept of genetic counselling with a group is not new to New Zealand, although this occurs within the context of a specific family rather than for individuals from several different families, as described by Ridge et al (2009). Genetic Services are able to offer genetic counselling to a whanau, or extended family, either in the hospital setting, or more rarely, on the marae or in a family home. These occasions offer an opportunity to respond to families in ways that are more culturally appropriate and that directly address the needs of that particular whanau. During the past ten years, I have occasionally been able to do a home visit or attend a whanau gathering to talk about an inherited cancer predisposition. The opportunity to meet with several generations of a family in their home or marae affords a somewhat different experience of genetic counselling, providing a response that is often more appropriate, and more comfortable, for the family. Unfortunately current resourcing levels mean that home visits are very rare events. Informal discussions with genetic counselling colleagues in New Zealand indicate that most genetic counsellors find the opportunity to attend a whanau gathering a rewarding way to offer genetic counselling to whanau groups, both Maori and Pakeha.
It may be that whanau meetings offer both a family-appropriate and cost-effective means of delivering services to some groups, with further research needed to explore this.

Meeting with an extended family provides the opportunity to understand the family experience of the illness or genetic condition and to see families in familiar environments where they are “at home” and comfortable. This helps to break down the power differences between health practitioners and clients, putting the family in the position of familiarity and power, because the practitioner is entering their environment and following their customs and protocols as information is shared. Family members who are struggling with the knowledge of increased risk are seen with family support that is often not present in the genetic clinic. While it is not practical to offer home visits or whanau meetings to everyone, this may be an appropriate way of delivering genetic counselling services to some groups. Port et al (2008) considered ways of meeting the needs of Maori with a range of genetic conditions including familial gastric cancer and recommended that Genetic Services develop practices that are responsive to traditional Maori beliefs regarding the collective ownership of genes and collective approaches to consent.

One of the limitations of this study is the absence of Maori women participants. The reasons why Maori women are not well represented in the genetic clinic are unclear, although this may reflect broader disparities in health care delivery in New Zealand. The provision of services in familiar settings, for example the local marae, may be a way to reach a group that is currently under-represented both in this study and in the genetic clinic.

9.5.4 Identifying those women who need additional support

One of the difficulties for health practitioners is to identify the women who may benefit from additional support and contact with the health system. During the interviews, several of the women who were struggling to “get on with it” expressed a desire for further contact with staff from Genetic Services or other hospital services. They indicated that they did not feel as though their assessment was complete or that they were unsure about surveillance. Although the interviewer urged several of them to
phone the Genetic Service, none of them subsequently made contact. One possible explanation for this is that these women do not feel that they are a priority, as one woman stated, or feel intimidated by the prospect of contacting the hospital service. This suggests that ways of identifying those individuals who may go on to experience challenges in accessing and managing surveillance are needed. Alternatively, putting in place robust systems of follow up or recall, for example an annual phone call by a genetic counsellor, may provide a way to reach this group.

The findings of this study suggest that one of the ways in which genetic counsellors and other health practitioners can get an indication of the way in which a woman is likely to approach her risk is to listen to the language that she uses. Women who struggle to “get on with it” often used language that described their relationship with medical professionals as “other” and in which they had less power. Conversely, women who are “getting on with it” tend to use language that describes a relationship in which the power is shared somewhat more equally between patient and doctor. Careful listening is one of the tools that genetic counsellors can use when seeking to provide appropriate care and follow up to their clients.

9.5.5 A word to health practitioners

It is worth noting that several women commented that their choices regarding risk management had been influenced directly by the use of language by medical professionals that they found offensive and degrading. There have been criticisms and critique of the language used by medical professionals when discussing women’s bodies since the 1970s, particularly arising out of the work of feminist writers (Koutroulis, 1990; Scully & Bart, 1978). Sociologists working in education recognise that textbooks are part of the occupational socialisation of students studying in a given field, containing both the overt content information and a more hidden curriculum consisting of the attitudes and values that will subsequently influence practice (Koutroulis, 1990). Scully and Bart (1978) first described the sexist ideology and patriarchal thinking that pervaded the obstetrics and gynaecology textbooks of the 1950s and 1960s, thereby describing a long history of pervasive negative attitudes towards women and their bodies by the medical profession. Glenda Koutroulis (1990) repeated a similar study eighteen years later and found that, while there had been some improvement, a content
analysis of obstetrics and gynaecology set texts for medical students continued to
demonstrate pervasive sexist and patriarchal attitudes towards women’s bodies. Emily
Martin (1994) describes widespread reference to a language of deficit and decay
describing menstruation and menopause in medical textbooks, further supporting the
indication that women’s bodies are undervalued and offered limited respect by some
medical professionals.

A similar style of language pervades the interactions that some of these women reported
with their doctors, with ovaries variously described as *empty petrol cans* and *shrivelled peas*. It seems obvious to suggest that doctors could alter their language to use terms
that show more respect for women’s bodies. However, despite this ongoing critique, the
reports of the women interviewed for this study indicate that there are still areas of
medicine where the language used is offensive to women and requires revision. It seems
likely that altering language that is entrenched in a historically patriarchal medical
system will take more than a request that individual doctors choose their words
carefully. A continued shift away from the historically sexist and derogatory language
found in medical school textbooks will form just part of a change in attitude and
behaviour towards women and their bodies. The growing acceptance of women in
medicine and the ever-increasing numbers of women entering medical training (Pringle,
1998) is also likely to contribute to shifting trends in both language use and in more
general attitudes towards women.

### 9.6 Limitations

The women who participated in this study are a homogeneous group. With the
exception of three women who had immigrated to New Zealand from Canada and South
Africa, they are all Pakeha New Zealanders. The majority of the women were well-
educated, with just over half the group having a tertiary qualification. They are
predominantly heterosexual and the majority are partnered or married. The
homogeneous nature of the group of participants is a significant limitation of this study
as it means that we continue to know little about the experiences of women who are
outside the demographic of the majority of the participants.
In a study of the New Zealand experience of living with an increased cancer risk, it is particularly disappointing that the participants were largely ethnically homogeneous. This limitation was present from the start of the study, with no Maori or Pacific women listed on the database that was used to invite study participation. The reasons for this are unclear, although it is likely to be a reflection of well reported disparities in access to medical care in New Zealand (Blakely et al, 2005; Priest et al, 2006; Sarfati et al, 2006). While these studies examining access to cancer screening services provide useful insight regarding disparity in accessing services by ethnic groups, at this stage access to Genetic Services has not been studied.

Further research is indicated to explore the ways Maori, Pacific and other ethnic groups in New Zealand experience familial cancer and living with increased cancer risk. In one of the only specifically New Zealand publications regarding genetic services, Port et al (2008) considered ways genetic services could be more appropriately delivered to Maori. They highlighted the need for recognition of Maori tikanga (belief systems) in both service provision and delivery, along with recognition of the hierarchical, tribal structures that contribute to shared decision making. Port et al’s (2008) work could be used in the development of research into both the role of genetic risk assessment for Maori whanau and the ways that they approach risk. An inherited predisposition to diffuse gastric cancer is more frequent among New Zealand Maori. A study examining the experience of Maori whanau with inherited gastric cancer would provide an opportunity to begin to understand how Maori whanau experience living with increased cancer risk. The findings of a study of that nature could be compared with the findings of this study, to elucidate whether “getting on with it” is associated with being Pakeha or whether this approach is also found among Maori.

The experiences of ethnic groups other than those with European ancestry are largely absent from the literature examining increased cancer risk at this stage. As noted in chapter one, few studies have included women of ethnicities other than those originally descended from Western European countries. Given migration patterns and ethnically diverse populations in countries such as the United Kingdom, North America and Australia, research to delineate the presence or absence of hereditary cancer risk amongst other ethnic groups, and to explore their experiences of living with an increased risk, is needed internationally.
The participants in this group represent a demographic that is well-educated, with the majority in paid employment at the time of their interview. They were invited to participate based on prior contact with the Gynaecological Oncology Service and almost all of them had had contact with Genetic Services, indicating that they are likely to reflect a similar demographic to the population seen in the genetic clinic. However they are not representative of the New Zealand population as a whole and therefore the findings should be considered in relation to the demographic that is represented. The homogeneity regarding high levels of education and paid employment status suggest that these participants are also likely to be among the more socially advantaged group of New Zealanders. One possible reason for the absence of a participant population that more accurately reflects the whole New Zealand population is that similar disparities in access to medical care as noted for Maori and Pacific peoples also exist for people who are socio-economically disadvantaged. They may not have access to the knowledge that genetic risk assessment is available or they may lack the resources needed to collect the necessary family history information. This study suggests the possibility of broader issues regarding access to Genetic Services for a significant group of New Zealanders. An examination of the disparities in access to Genetic Services should include education and employment status along with ethnicity. A consideration of the ways that other groups of our population approach cancer risk would also contribute to our understanding of the relevance of the theorising regarding risk as a concept of late modernity.

The findings of this study are drawn from retrospective accounts of women who had been living with the knowledge of their increased cancer risk for some time. The opportunity to be interviewed for the study afforded each woman the space to reflect on her experiences with a willing and interested listener. Their transcripts are therefore very likely to include the hindsight that comes with time to reflect on their experiences. The majority of the women in this study report a narrative of “getting on with” their cancer risk. Some of them describe the initial distress at learning of their increased risk and the difficulties associated with making decisions about the management of the risk. The narrative of “getting on with it” may be one that develops over time. The findings should therefore be understood in this context, suggesting that while women may indeed “get on with” life with increased risk, they may experience initial distress and upheaval that is not reflected in this retrospective study. Our understanding of the initial
experience of learning about increased risk could be enhanced by a prospective study that followed women through the experience of genetic counselling and receiving results, with further interviews in the year following receiving their genetic test result.

9.7 Reflections on the journey

When I began this project, it was with the desire to better understand the experiences of a group of women with whom I was working in my clinical role. I had the naïve belief that I could keep each role and the concomitant learning and insight in separate compartments. During some parts of each week I would be a genetic counsellor and during other parts of the week I would be a researcher. As discussed in chapter four, I very quickly realised that separating my clinical learning from my research learning was impossible and that what was needed was a means to incorporate the two roles and let them inform each other. With time, I came to think of myself as an outsider alongside the participants and to practice reflexive research.

The opportunity to reflect on the experiences of the group of women who struggle to “get on with it” has provided some of the most important personal learning that has arisen out of this thesis. In seeking to understand their experiences, I have come face to face with my own prejudices and inclinations, and have been given an opportunity to consider the ways in which these impinge on the interactions that I have with clients. While it is likely that we will make connections with those clients who have a similar world view to our own, it is also true that it is often out of seeking to understand different perspectives that we learn most. Undertaking this research has allowed me the freedom to talk about, write about and reflect upon the frustration I initially felt with the stories of the women who struggle to “get on with it”, and to start to explore ways that the system reinforces the challenges these women face. As individuals who have chosen to work in the “helping professions” I and many of my colleagues would consider ourselves to be kind, caring, thoughtful people who want the best for our clients. Sometimes the best of intentions become lost in a large system that, for reasons related to size and budget constraints, can forget to treat each person as the individual that they are and instead treats everyone in the same way.
Consider the woman who is worried about developing breast cancer but has not booked a mammogram despite having the form from the doctor, the woman who declined all offers of counselling despite being devastated and depressed by receiving a positive BRCA test result. The recommendations might seem quite obvious. Book the mammogram. Go and talk to a counsellor. And indeed, these conclusions are what the ideals of neo-liberal governance would suggest should happen. But these women are up against structural powers, including a historically patriarchal medical system and systemic processes that require individuals to know how the system works to access tests and consultations.

The follow up that Genetic Services currently offer individuals who carry inherited cancer gene mutations is limited to a phone call in the days following the positive test result disclosure. Women in the Wellington region may be seen again during the multi-disciplinary breast clinic, providing an opportunity for further follow up and discussion. It is clear that some of the women interviewed for this study would have found ongoing contact with Genetic Services over the years helpful, both for further discussion regarding the chance of developing cancer and to ensure they have access to appropriate surveillance. An annual telephone call could provide women with the opportunity for discussion of any questions, a forum to check their understanding of risk management options, and a means of facilitating attendance for surveillance if desired by the individual. Forrest et al (2008) showed that contact several months after results were given was useful in assisting people with telling their family about the cancer predisposition. While their intervention was specifically designed to assist with family communication, similar, relatively simple interventions such as telephone calls provide opportunities to address the specific concerns of women living with an increased risk of cancer.

My own experiences of the medical system illustrate all too clearly how difficult it can be to negotiate. Experiences such as being kept waiting for long periods with no explanation, the limited privacy afforded by doctors leaving doors ajar or being interrupted by colleagues, as well as the disempowering aspects of physical examinations all combine to make hospital visits intimidating. One woman reported that having to take her shirt off regularly for examination felt degrading. As described above, another woman reported that the behaviour of a senior consultant towards junior staff members left her feeling uncomfortable and frustrated.
Several of the participants reported that they or their family members were health practitioners. They indicated ways that they had used this status to help them negotiate the system and collect information that they used in decision making. However, while health provider status may be of assistance in navigating hospital systems, there is evidence to indicate that it does not always result in better or even adequate care. Duke and Connor (2008) examined the experiences of a small group of senior nurses in Australia and New Zealand who had experienced serious illness and found that, while some nurses had experienced special care, others had experienced meagre care. Health practitioners can learn from their own experiences of the health system as they seek to make services more accessible to the population they serve.

The learning afforded by being a practitioner-researcher has informed my clinical practice during the course of this project. While the learning is largely confined to my own practice, the benefits and tensions associated with combining clinical practice with research deserve further consideration. Genetic counselling is a relatively new profession in Australasia with limited research regarding practice undertaken to date. With the introduction of the two year clinical masters degree in genetic counselling as the entry level qualification, and the requirement that all students complete a research dissertation, the profession is likely to see increasing numbers of genetic counsellors in clinical practice and participating in research. The development of a forum for genetic counsellors combining research and clinical practice would provide opportunities to share the tensions and insights and contribute to the literature emerging from other fields where research is being done by people who are also working with their participant group.

9.8 The value of using women’s stories in genetic counselling research

The methodological approach used in this study has utility for genetic counselling research, offering an approach which allows us to develop a deeper understanding of the experiences of our clients both within and, more importantly, beyond the genetic counselling clinic. This thesis has used the stories told during interviews with a group of thirty-two women to present a narrative that describes their experiences and interprets them through the lens of the wider temporal, cultural and social contexts within which their experiences occurred. As Beeson (1997) noted, qualitative research methods are
about meaning. The use of qualitative approaches such as the thematic narrative analysis presented here “enables us to discover and document aspects of reality that we cannot necessarily anticipate, and thus to transcend the limitations of our own perspective. It can explain not only what people do, but why they do so” (Beeson, 1997, p. 24). This type of interpretive approach is valuable in the field of genetic counselling research because it results in narratives that can sensitize genetic counsellors to the range of possible responses that we might see in clients (Grubs & Piantanida, 2010). In addition, it helps us to understand why clients may respond in particular ways, and these understandings can inform our practice.

Narratives are composed for particular audiences and allow researchers to draw on the dominant discourses of the time to interpret their data (Riessman, 2008). Writing nearly fifteen years ago, Beeson (1997) observed that genetic counsellors are in a strong position to do this type of research because they are already positioned between two very different social worlds – that of molecular genetics and the often highly emotional and subjective worlds of the families they work with. In choosing to present my analysis in a way that draws strongly on the thematic narrative approach described by Riessman (2008), I have demonstrated the way in which a practitioner-researcher can undertake research that helps to deepen our understanding of the experiences of our clients.

9.9 Recommendations for clinical practice

The findings from this study inform genetic counselling practice in New Zealand and have wider implications for health practitioners working with women who have an inherited predisposition to developing breast and ovarian cancer. The stories these women tell are ones that indicate resilience and a readiness to use genetic information to manage or reduce their risk. Genetic counsellors and other health practitioners can support these women to “get on with” their lives in a number of ways.

The provision of information is crucial to these women. This finding has implications for clinical practice, with women indicating that they want more information and that they want the information to be tailored to them as individuals. Information that is provided in consultations with health professionals can be supplemented by written information, resources such as DVDs and computer assisted decision aids and by
suggestions about internet sites women may find helpful. Further research to elucidate the appropriateness of various means of providing information is required to identify resources that are best suited to the needs of the New Zealand population.

Multi-disciplinary clinics offer a means of grouping health professionals and offering women a more comprehensive service. Genetic counsellors are ideally placed to engage with medical professionals and facilitate the development and running of multi-disciplinary clinics. These clinics offer a means of regular follow up for women, and funded travel to the clinics offers a way to help overcome the isolation and lack of specialist care that some women experience. Research to explore women’s experiences of attending the existing multi-disciplinary clinic could be used to inform the development of this model of care elsewhere in New Zealand.

Genetic risk assessment and testing is, in some respects, a form of preventive health care. The provision of adequate resourcing and funding for genetic counselling, genetic testing, medical surveillance and risk reducing surgery has the potential to result in significant savings. These savings come both in the form of financial savings in oncology treatment, and, more importantly, they result in lives saved. As these women’s narratives so clearly say, they want to watch their children grow up, and they want to live.

9.10 Conclusion

I always knew I was going to have the test done, but why did I?
Because I wanted to know, I wanted to know because I watched Mum die and I thought yep I’ve got to know [29].

Why do women seek to clarify and understand their chance of developing breast and ovarian cancer? This woman states that, quite simply, she had to know. She frames this statement with the information that she had watched her mother die, with the unspoken implication that she did not want the same thing to happen to her. The test showed that she had inherited a BRCA mutation and she went on to have her breasts and ovaries removed. Her story is one that very vividly represents the way in which this group of women “get on with” living with their increased cancer risk. The initial decision regarding genetic testing took her a year to make. Learning that she carried the familial
BRCA mutation was so distressing that she was unable to drive home from the appointment. However, once the initial shock had passed, she almost immediately arranged to have a risk reducing salpingo-oophorectomy. The decision to have risk reducing mastectomy was made on the way home from the appointment to collect her results, although the surgery itself occurred many months later.

A few months ago she approached me after I had given a presentation of this work at a conference for families with BRCA mutations. Having completed her own surgeries, she was now actively involved in supporting other women through their own decision making. She told me that she had no regrets about her decisions.

Like many of the other women who participated in this work, she was clear that she would not change her decisions regarding genetic testing and risk management. These women have demonstrated that they are able to assimilate the chance of developing cancer into their everyday lives. Many of them use a deeply familiar and socially accepted identity as mothers to motivate their decisions regarding medical management of their cancer risk. Being at increased risk of developing cancer is just one aspect of their lives and their selves, an aspect which the majority of them appear to do what they can to manage while “getting on with” the business of living. I wish them, and the many women who I have worked with in the past nine years and who have contributed in so many ways to my understanding of this data, contentment, life and laughter.
**BRCA1** A human tumour suppressor gene found on the long arm of chromosome 17. BRCA1 has a role in DNA repair. When functioning BRCA1 is protective against the development of certain cancers including breast, ovarian and prostate cancer.

**BRCA2** A human tumour suppressor gene found on the long arm of chromosome 13. BRCA2 has a role in DNA repair. When functioning BRCA2 is protective against the development of certain cancers including breast, ovarian and prostate cancer.

**CA125** Cancer antigen 125 has a role as a tumour marker for ovarian cancer. It can be used in monitoring women for signs of recurrence of ovarian malignancy. As it may also be elevated in other malignancies and in benign conditions including endometriosis, it has not been effective as a screening tool for the early detection of ovarian cancer.

**Central and Southern Regional Genetic Service (C&SRGS)** Genetic Service based in Wellington and Christchurch, New Zealand, which serves the populations south of a line from Taranaki to Hawkes Bay.

**Deoxyribonucleic acid (DNA)** The molecule that encodes the genes responsible for the structure and function of living organisms and allows the transmission of genetic information from generation to generation (Nussbaum et al, 2001).

**Gene** A hereditary unit; in molecular terms, a sequence of chromosomal DNA that is required for the production of a functional product (Nussbaum et al, 2001).
**Hereditary non-polyposis colorectal cancer (HNPCC)** This term has been used interchangeably with the term Lynch syndrome to describe an autosomal dominantly inherited cancer predisposition syndrome caused by mutations in the mismatch repair genes.

**Lynch syndrome** An autosomal dominant genetic condition predisposing to cancers including colorectal, endometrial, ovarian, gastric, cancer of the small intestine, hepatobiliary tract, urinary tract and brain. Lynch syndrome is caused by mutations in the mismatch repair genes.

**Mismatch repair genes** The mismatch repair genes are a group of genes involved in the repair of DNA transcription errors that arise during DNA replication.

**MSH2** Mismatch repair gene. Mutations in MSH2 and the other mismatch repair genes are associated with Lynch syndrome or HNPCC.

**Mutation** A permanent heritable change in the sequence of genomic DNA. In general, the term mutation applies to a pathogenic change which is associated with a deleterious outcome.

**Northern Regional Genetic Service (NRGS)** Genetic Service based in Auckland, New Zealand, serving the population north of a line from Taranaki to Hawkes Bay.

**Occult fallopian tube cancer** A cancer originating in the fallopian tube discovered at the time of risk reducing salpingo-oophorectomy or during the pathological examination of the tissue after surgery. No signs or symptoms of cancer were noted prior to surgery.
Pre-implantation genetic diagnosis (PGD) The term given to several possible procedures which may be performed on an oocyte or embryo prior to implantation. It is used as an adjunct to in vitro fertilization (IVF) to test embryos for inherited conditions where the causative mutation is known.

Prophylactic surgery A surgical procedure designed to prevent a disease rather than to cure or treat it. Both mastectomies and salpingo-oophorectomy can be done as prophylactic surgery.

Risk reducing surgery With the recognition that after prophylactic mastectomy and/or salpingo-oophorectomy a residual risk of developing breast or primary peritoneal cancer remains, there has been a trend away from calling these surgeries prophylactic and increasing use of the words risk reducing.

Salpingo-oophorectomy Surgical removal of the ovaries and fallopian tubes. May be unilateral or bilateral.
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Appendix 1

Dr Alison McEwen
Central Regional Genetic Services
Wellington Hospital
PB 7622
Wellington South

Dear Alison,

MEC/00/7/067
New Zealand Woman living with an increased risk of hereditary ovarian cancer

Thank you for the above application which was considered by Multi-Region Ethics Committee at its meeting on 16 July 2006 and approved subject to the following conditions.

Requirements:

<table>
<thead>
<tr>
<th>Requirement</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>✔️ 1) National Application Form, pg 2, Q9</td>
<td>Confirm that this study is using a national database. If not, it must be resubmitted to the Central Ethics Committee.</td>
</tr>
<tr>
<td>✔️ 2) National Application Form, pg 9, B.10</td>
<td>Non-English-speakers are excluded. This is not consistent with the Consent Form, which provides for an interpreter. It is recommended that non-English-speakers be included.</td>
</tr>
<tr>
<td>✔️ 3) National Application Form, pg 11, D1</td>
<td>Provide evidence that authority has been given to access the Gynaecological Service Database at CCDII.</td>
</tr>
<tr>
<td>✔️ 4) Locality assessment</td>
<td>Please complete all parts of this form. (Refer to point (3) above)</td>
</tr>
<tr>
<td>✔️ 5) National Application Form, pg 11, D2, D3 and D4</td>
<td>The invitation letter should be sent from the gynaecological consultant who has a relationship with the patient, and is privy to the information that she is high-risk, not from the researcher.</td>
</tr>
<tr>
<td>✔️ 6) National Application Form, pg 14, section F</td>
<td>Please provide evidence of consultation with an appropriate Maori group.</td>
</tr>
<tr>
<td>✔️ 7) Invitation letter dated September 2006</td>
<td>Please clarify whether the “enclosed form provided” is the Consent Form. Consent should not be obtained in this way, but should rather be obtained in person.</td>
</tr>
<tr>
<td>✔️ 8) Invitation letter dated September 2006</td>
<td>State that participation in the study is voluntary.</td>
</tr>
<tr>
<td>10) Patient Information Sheet</td>
<td>Clarify what part of the study women are consenting to participate in.</td>
</tr>
</tbody>
</table>

**Comments:**

| 1) Initial letter to research team, dated 26th May 2006 | To refer to “The capture of women…” is objectionable. |

Please forward your response in letter format with an updated information sheet/consent form and other required forms to the Committee Administrator. Your response will be reviewed by a committee member and if the above points have been addressed to their satisfaction, final ethics approval will be given by the Chairperson under delegated authority.

Your response will be checked by the Administrator and a letter of approval forwarded if all the above points have been satisfactorily addressed.

The Committee forwards the following comments, advice and suggested amendments which do not affect the application’s ethical approval status.

*Please forward three copies of your responses to the Committee Administrators.*

If you have any queries, please contact me.

Yours sincerely

Michelle Judge  
Multi-region Ethics Committee Administrator  
email: michelle.judge@moh.govt.nz
11 October 2006

Michelle Judge and Sue Fish
Multi-region Ethics Committee Administrator
Ministry of Health
PO Box 5013
Wellington

Dear Michelle and Sue,

Re: MEC/06/07/067
NZ women living with an increased risk of hereditary ovarian cancer

Thank you for the letter about my application to the multi-region ethics committee regarding the above project.

1. In the letter dated 20/07/06, the first requirement the committee have requested is confirmation that the study is using a national database. The study is not using a national database, it is using a database that is administered by the gynaecological oncology service at CCDHB. However, there are women on this database who live in more than one of the regional ethics committee areas. Specifically, there are women on this database who live in the Nelson Marlborough DHB area, and those who are therefore live in an area administered by the Upper South Region Ethics Committee. There are also women who live in the Wellington and Manawatu areas who are therefore live in areas administered by the Central Region Ethics Committee. Prior to submitting the ethics application I went to the website to determine which ethics committee I should apply to. The following statement comes from the website:

The Multi Region Ethics Committee is responsible for reviewing health and disability research studies that either:

- have study locations in more than one ethics committee region
- are actively recruiting participants in more than one ethics committee region; or
- use a database, samples or other information gathered from more than one ethics committee region.

Our study hopes to actively recruit participants from more than one ethics committee region, so I applied to the multi-region ethics committee. I was therefore not surprised to then be told that I had to confirm that the study was using a national database. I contacted Sue by email on 29/08/06 and she has confirmed that it was inappropriate for me to apply to the Multi-region Ethics Committee.

2. We have removed the requirement for participants to be English language speakers. Point R 10 on Pg 8 now reads:
The participants must be:
- 18 years or over
- Carry a BRCA1 or 2 mutation or be at high risk of developing breast and/or ovarian cancer on the basis of family history

3. All potential study participants are being followed by Mr Dyna McConnell, Consultant Gynaecological Oncologist at CCDHB. Mr McConnell is one of the co-investigators for this study. Mr McConnell administers the database of the group of women we hope will participate in the study and therefore we have his authority to access the information on the database. Mr McConnell is happy to discuss this with you and can be contacted at [Contact Information]

Sincerely,

[Signature]

[Name]
02157554. Mr John Tait, the Clinical Director of Women's Health at CCDHB has also approved the use of the information on this database (see attached Locality Assessment form).

4. It is unclear as to which sections of the locality assessment form are not complete. The research proposal has been reviewed by Mr John Tait, the Clinical Director of Women's Health at CCDHB and he has signed the locality assessment form. The gynaecological oncology service is part of the Women's Health Service at Wellington Hospital. Please let me know if you require further information.

5. The invitation letter has been re-written and will now be sent by Mr Dyne McConnell, Consultant Gynaecological Oncologist. A copy of the new letter of invitation is attached.

6. We have consulted with the Ngati Tama Research Consultation Committee (NTRCC) and evidence of this consultation is attached. We consulted with the NTRCC as I am enrolled as a masters student at Otago University and therefore have access to a formal pathway for Maori consultation. As you are aware from our earlier application, we have also approached the Maori Health Unit (now called Whanau Care Services) at Wellington Hospital on several occasions. We have not received a response from this group.

7. Written consent to participate in the study will be obtained by Alison Gray prior to commencing each interview. The "enclosed form provided" that we refer to in the invitation letter is attached. We omitted to include this form in the original application to the ethics committee.

8. The letter now includes a sentence which says: Participation in this study is voluntary.

9. We have always intended to go through a separate consent process prior to compiling a book of the women’s stories. We have re-worded the sentence in the invitation letter to make this fact more explicit. The re-worded sentence now reads: We will contact you again prior to including your story in a publication, to obtain written consent for your story to be included.

10. We have re-written parts of the patient information sheet to clarify what the women are consenting to. A copy of the revised information sheet is attached. Under question #2 on the information sheet we have added the following sentence: Before starting the interview, Alison will talk through the consent form with you and ask you to sign it. We will ask for your consent to participate in the research study. Later, we might contact you again to ask for permission to use your story in a book of stories about living with an increased risk of cancer. Under question #4 on the information sheet we have specified that we will contact the women again to obtain written consent to include their story in a publication.

Yours sincerely

[Signature]

Alison McEwen
Genetic Counsellor
Dear

I am writing to invite you to take part in a study investigating what it is like to live with an increased risk of ovarian cancer because of one’s family history and/or because one carries a BRCA1/2 mutation.

I obtained your name from records kept by the Gynaecological Oncology Service at Wellington Hospital. This letter is being sent to all the women who are included on the Gynaecological Oncology Service database at Capital and Coast DHB who are identified as having an increased risk of hereditary ovarian cancer. If you have not had a consultation about ovarian cancer risk it is likely that you have received this letter in error. If this is the case, please accept my apologies and call Alison McEwen toll-free on 0508-364-436 so that the database can be corrected.

Participation in this study is voluntary. Participation in the study involves an interview, either face-to-face or by phone, at a time and place that suits you. The interviews will be conducted by Alison Gray, who is an independent researcher. After the interview the tapes will be transcribed and the script returned to you so that you can make sure you are happy with what you said during the interview. When you return the script, we will study the information in detail. I enclose an information sheet that provides more detail about the study.
I hope that this study will help us to better understand:

- what it is like to live with an increased risk of developing cancer
- what it is like to attend a genetic counselling appointment
- the information and support needs that women in this situation have.

I have received ethical approval to conduct this project from the Multi-Region Ethics Committee. The funding for the project has come from a grant from the Todd Foundation Centenary Fund. The principal researcher for this project is Alison McEwen, a Genetic Associate at the Central and Southern Regional Genetic Service. If you would like to find out more about what is involved in the study, please contact Alison McEwen toll-free on 0508-364-436 or by email at: Alison.McEwen@ccdhb.org.nz

If you would like to find out more about the study please complete and return the enclosed form in the envelope provided.

I look forward to hearing from you.

Yours sincerely

Mr Dynes McConnell

Consultant Gynaecological Oncologist
Research Study: Information Sheet

You are invited to take part in a research study to look at the experience of New Zealand women who have been assessed by Genetic Services as being at potentially high risk of developing breast and/or ovarian cancer.

1) What is the study for and why is it being done?
The overall aim of this study is to find out what it is like to live with an increased risk of ovarian cancer because you have a family history of this disease and/or because you carry a BRCA1/2 mutation. The study will involve a series of interviews with New Zealand women who have an increased risk of ovarian cancer. The interviews will include questions about your genetic counselling experience, the way you are making decisions about genetic testing and about how to manage your cancer risk, and the ways that this information and these decisions impact on your lives. We think this study will be invaluable in helping us to understand the unique needs of New Zealand women in this situation. We hope that we will gather enough information to compile a book of stories about living with an increased risk of cancer.

2) What would I be asked to do if I took part in this study?
The study involves having an interview with an experienced independent researcher (Alison Gray). Alison will contact you to arrange a time that suits you to be interviewed. You can choose where to have the interview, for example you might choose to be interviewed at home or at work. Alison would prefer to meet you for the interview, but there is also the option of being interviewed by phone if you would prefer that. The interview will be tape-recorded and transcribed. We will then return your interview transcript to you so that you can make sure that you are happy with what you said during the interview. Before starting the interview, Alison will talk through the consent form with you and ask you to sign it. We will ask for your consent to participate in the research study. Later, we might contact you again to ask for permission to use your story in a book of stories about living with an increased risk of cancer.
3) **Are there any costs associated with the study?**

There are no costs to you from being involved in the study. The interview will be conducted either in person at a location of your choice (eg home or office), or by phone, with the researcher calling you at an agreed time.

4) **What will be done with this information?**

The interviews will be transcribed so that we have a written record of each interview. These records will be stored securely and will not be used for any other study without your permission. When the interviews are completed we will send you a copy of a report that describes what we have learnt. We will also write articles about the study and publish these, or talk about the study at conferences, so that other people will be helped by the information. It will not be possible to identify any of the research participants in the material we present or publish. Ultimately, we would like to use the stories that we collect to compile a book about the experience of being at high risk for hereditary cancer. We will contact you again to obtain written consent to include your story in a publication. All of the information will remain confidential and no information which could identify you or your family will be used in any reports or writing from the study.

5) **Do I have to take part in the study?**

No, not at all. You should only take part in this study if you want to be involved. If you choose not to take part it will not affect your usual care or treatment in any way.

6) **Can I change my mind later if I decide to participate?**

Yes, you can choose to leave the study at any time. This will not affect your care or treatment in any way.

7) **Will the study benefit me in any way?**

We can’t be certain that you will get any benefit from taking part, but we have had anecdotal reports from other researchers that some women find it helpful to talk about their experiences with a person who is not involved in their care or surveillance.
8) **Do you have permission to do the study?**
We have permission from the Multi-Region Ethics Committee to do this study.

9) **What if I have other questions about the study?**
Please contact Alison McEwen (Genetic Associate) toll-free on 0508-364-436 or Dynes McConnell (Gynaecological Oncologist) on 04-3855999.

If you have any questions or concerns about your rights as a participant in this study you may wish to contact the Health and Disability Advocate Mid and Lower North Island 0800 42 36 38 (0800 4 ADNET).
## Appendix 3

Participant demographics and surgical status at time of interview.

<table>
<thead>
<tr>
<th>#</th>
<th>Age</th>
<th>Marital status</th>
<th>Children</th>
<th>Mutation status</th>
<th>City/Region</th>
<th>Cancer diagnosis</th>
<th>Risk-reducing Salpingo-oophorectomy</th>
<th>Risk-reducing mastectomy</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>47</td>
<td>M</td>
<td>3</td>
<td>BRCA1</td>
<td>City</td>
<td>Bilateral breast</td>
<td>No</td>
<td>N/A</td>
</tr>
<tr>
<td>2</td>
<td>56</td>
<td>M</td>
<td>1</td>
<td>MSH2</td>
<td>City</td>
<td>Ovarian</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>3</td>
<td>31</td>
<td>M</td>
<td>1</td>
<td>No testing</td>
<td>City</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>4</td>
<td>52</td>
<td>M</td>
<td>3</td>
<td>BRCA1</td>
<td>City</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>5</td>
<td>42</td>
<td>S</td>
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<td>No testing</td>
<td>City</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>6</td>
<td>43</td>
<td>M</td>
<td>3</td>
<td>No testing</td>
<td>City</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>7</td>
<td>59</td>
<td>M</td>
<td>0</td>
<td>BRCA2</td>
<td>City</td>
<td>Bilateral breast, melanoma</td>
<td>Yes, occult fallopian tube cancer</td>
<td>N/A</td>
</tr>
<tr>
<td>8</td>
<td>46</td>
<td>P</td>
<td>2</td>
<td>No testing</td>
<td>City</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>9</td>
<td>36</td>
<td>P</td>
<td>0</td>
<td>BRCA1</td>
<td>City</td>
<td>Breast</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>10</td>
<td>50</td>
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<td>City</td>
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M – Married
S – Single
P – Partner
N/A – not applicable

No testing – no genetic testing done in this individual. Uninformative testing may have been done in another family member, or there may not have been a living affected family member available for testing.

No mutation – BRCA testing offered and accepted, no mutation identified.
Appendix 4
Appendix 5
Topic Guide for In-Depth Interviews
Hereditary Ovarian Cancer Project
Version 1

Demographic characteristics including:
date of birth, ethnicity, education level, employment, children

Personal experience of cancer:
breast/ovarian/other, age at diagnosis,

Family/whanau history of cancer:
Personal experience of relatives with ovarian or breast cancer, age, relationship, feelings about cancer in the family, growing up with cancer.

Beliefs about cancer - survivable disease/everyone dies, attitude

Knowledge about hereditary ovarian cancer in general, personal risk perception, management choices to date

BRCA mutation status - BRCA1/2, age when tested, how long ago, proband/predictive test, certainty/uncertainty and effect on decision-making

Genetic testing – decision-making, impact on self, family/whanau, intimate relationships, feelings during testing process, feelings now

Information needs – sources of information, responsibility for information, gaps
Sources of support, responsibility, gaps

Trust – of information, providers

Impact of knowledge about increased risk on daily life, decisions about having children, employment, relationships, anxiety

Changes over time in living with increased risk

Thoughts on coping with increased risk – strategies,

Thoughts about body image, feelings of self worth, sexuality, intimate relationships, changes in perception with knowledge of increased risk

Genetic counselling – understanding of contribution of service prior to 1st contact, subsequent understanding, experience in general, letter, follow up, gaps in service
Appendix 6

Topic Guide for In-Depth Interviews

Hereditary Ovarian Cancer Project

Final Version

Demographic characteristics including: date of birth, ethnicity, education level, employment, children

**Background**

Can we begin with you telling me how you came to be involved in this cancer project?

Family/whanau history of cancer: Personal experience of relatives with ovarian or breast cancer, age, relationship, feelings about cancer in the family, growing up with cancer.

Personal experience of cancer: breast/ovarian/other, age at diagnosis

**Beliefs/feelings**

Beliefs about cancer as an illness - survivable disease/everyone dies, attitude

Can we talk a bit about your risk of breast and/or ovarian cancer and your sense of yourself as a woman – for example, how do you feel about your body? Do you feel differently about your body knowing about the increased risk for ovarian cancer? How?

How important is feeling good about your body compared with getting cancer? Would your feelings about your body affect the kinds of decisions you have made/might make? In what way?

*Nb: If idea of vulnerability is raised, please explore this*
Your risk of/ experience of cancer can also have an effect on your relationships with other people, especially with your partner. How has that been for you? – husband/partner; other family members; friends

Do you experience your relationships differently? How?

Does the awareness of the increased risk of cancer affect your daily life? How?

Knowledge/ management choices

Knowledge about hereditary ovarian cancer in general, personal risk perception, management choices to date

For those who have been offered genetic testing: decision-making, impact on self, family/whanau, intimate relationships, feelings during testing process, feelings now

BRCA mutation status - BRCA1/2, age when tested, how long ago, proband/predictive test, certainty/uncertainty and effect on decision-making

Impact of knowledge about increased risk on daily life, decisions about having children, employment, relationships, anxiety

Changes over time in living with increased risk - thoughts on coping with increased risk – strategies

Getting information

Information needs – sources of information, responsibility for information, gaps

Sources of support, responsibility, gaps
Trust – of information, providers

Genetic counselling – understanding of contribution of service prior to 1st contact, subsequent understanding, experience in general, letter, follow up, gaps in service
Appendix 7

CONSENT FORM

“New Zealand women living with an increased risk of hereditary breast and/or ovarian cancer: A qualitative study”

REQUEST FOR INTERPRETER
(to be included on all consent forms)

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<td>Ae</td>
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<tr>
<td>Niuean</td>
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I have read and I understand the information sheet dated 31 October 2006 for participants in this study. The study looks at what it is like to live with an increased risk of ovarian cancer because you have a family history of this disease and/or because you carry a BRCA1/2 mutation in New Zealand. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I have had the opportunity to use a friend to help me ask questions and understand the study.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my continuing or future health care.

I have had this project explained to me by ________________________________.
I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.

I understand that the researchers will contact me again if they wish to use my story in a book about living with an increased risk of cancer.

I have had time to consider whether to take part.

I know whom to contact if I have any questions or concerns about the study.

I consent to my interview being audio-taped.

I would like the researcher to send me a report discussing the outcomes of the study.

YES/NO

I __________________________ hereby consent to take part in this study.

Date

Signature  Signature of witness

Full names of researchers  Name of witness

Contact phone number for researchers: 0508-364-436
Project explained by:

Project role

Signature

Date

(Note: A copy of the consent form to be retained by participant and (in the case of patients) a copy to be placed in the medical file.)