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Saying 'No': A biographical analysis of the experiences of women with a genetic predisposition to developing breast/ovarian cancer who reject risk reducing surgery

Doreen Molloy
Edith Cowan University

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Saying 'No': A biographical analysis of the experiences of
women with a genetic predisposition to developing
breast/ovarian cancer who reject risk reducing surgery.

Thesis submitted by Doreen Molloy
MSc (Med Sci), BA, RGN, PGCTLHE

FOR THE DEGREE OF DOCTOR OF PHILOSOPHY
In the Faculty of Health, Engineering and Science
Edith Cowan University

11th August 2015

ABSTRACT

Background: Genetic technologies have identified some of the genes implicated in cancer susceptibility. Women with mutations in breast/ovarian cancer-susceptibility genes (BRCA1 and 2) have a lifetime combined risk of breast/ovarian cancer of more than 80%. Risk reducing surgery (RRS) reduces cancer risk by as much as 90% in high risk populations. Despite this, some BRCA1/2 mutation-positive women say no to RRS.

Purpose: To illuminate an understanding of why women at high risk of developing breast/ovarian cancer say no to risk reducing surgery (RRS).

Design: Denzin's (1989) interpretive biography was combined with Dolby-Stahl's (1985) literary folkloristic methodology to provide a contextualised narrative of the life experiences of six high risk women who said no to RRS. The participants' stories were captured through semi-structured interviews then read and interpreted through the lenses of three literary theories namely Marxist, Foucauldian and Feminist.

Findings: Different understandings of risk were central to the decision to say no to RRS. RRS was understood as a risk to body and self which superseded the genetic risk of cancer. However despite having the strength to keep their still-healthy bodies intact, the participants benchmarked their decisions to say no against the dominant discourse on cancer risk, leaving them in an unending state of flux as to whether they had made the right decision. The participants shared a genetic pessimism but there also existed an emergent private folklore which illuminated how they attempted to make sense of their experiences and negotiate the conflicts and contradictions thrown up by competing discourses.

Conclusions: The relationship between genetic testing and cancer prevention strategies is not straightforward and genetic information has the potential to harm as well as help high risk women. It is important health care providers approach this area from the viewpoints of those directly involved since without understanding; strategies to support these women may be ineffective.

The declaration page
is not included in this version of the thesis

CONTRIBUTION OF OTHERS

This thesis has been made possible with the support of the following people;

Principle Supervisor

Dr Joyce Hendricks, Faculty of Health, Engineering and Science, Edith Cowan University.

Associate Supervisor (2012 – current)

Professor Anne Williams, School of Health Professions, Murdoch University.

Associate Supervisor (2010 – 2012)

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Thank you.

Preamble

When Oscar-winning actor Angelina Jolie announced in the New York Times on 14th May 2013 that she had undergone bilateral risk reducing mastectomy followed by reconstruction with breast implants, the world took notice. Jolie's editorial in the New York Times (2013, May 14), entitled "My Medical Choice", described her decision to undertake RRS after she tested positive for a BRCA1 gene mutation which significantly increased her risk of developing breast and ovarian cancer.

Jolie's mother died from ovarian cancer aged 56. Her aunt had breast cancer and died shortly after Jolie's editorial was published. Jolie's lifetime risk of developing breast cancer was estimated to be 87%, and ovarian cancer, 50%. Jolie stated "I decided to be proactive and to minimise the risk as much I could" (Jolie, 2013, para 5), a decision her partner Brad Pitt described as "absolutely heroic" (Pitt, 2013, cited in Messer, 2013, para 2). Jolie (2013, para 11) further explained her decision:

I wanted to write this to tell other women that the decision to have a mastectomy was not easy. But it is one I am very happy that I made. My chances of developing breast cancer have dropped from 87 percent to under 5 percent. I can tell my children that they don't need to fear they will lose me to breast cancer. (...) and they know that I love them and will do anything to be with them as long as I can. On a personal note, I do not feel any less of a woman. I feel empowered that I made a strong choice that in no way diminishes my femininity.... I want to encourage every woman, especially if you have a family history of breast or ovarian cancer, to seek out the information and medical experts who can help you through this aspect of your life, and to make your own informed choices.

Angelina Jolie's familial cancer story made headline news around the world and sparked extensive media, medical and public debate regarding the sensibility or not of having one's healthy breasts removed in order to prevent cancer developing. Her editorial attracted more than 1700 reader comments compared with 170 for an editorial following the Boston Marathon bombings (List, 2013). Macmillan Cancer Relief, a leading United Kingdom (UK) Cancer Charity, reported an 1140% increase in visits to the online genetic breast cancer self-assessment tool (Macmillan Cancer

Relief, 2013) and the number of women undergoing genetic testing for breast/ovarian cancer doubled in some areas of North America (Chustecka, 2014). Cancer Council Australia similarly reported an 866% increase in women phoning their help line as a result of the 'Angelina effect' (Chustecka, 2014). Dr Allan Spigelman, director of Sydney's Kinghorn Cancer Centre not only predicted increased numbers of women undergoing genetic testing worldwide, but also hinted at the sensibility of Jolie's decision given her genetic status:

I fully anticipate there will be very significantly renewed interest in breast cancer gene testing across the world as a result of this high-profile person very sadly carrying the gene change but very bravely going ahead to have preventative surgery. ("Jolie's mastectomy revelation" ABC news, 2013, May 15)

The furore surrounding Angelina Jolie's breasts reflects Western society's obsession with the female breast (Thomas, 2006) and public ownership of female body parts (Millsted & Frith, 2003). Jolie's story and the prominence attached to it also exposes the public's fascination with genetics and genetic testing (Royal et al., 2010) and the perceived importance of genetics in everyday life (Anderson, 2002; Bates, 2005). Warnings that genetics services would be unable to cope with demand highlighted the almost panic reaction to the news of Jolie's surgery and the significance afforded to breast/ovarian cancer genetics and RRS.

The overall message from Jolie's story was clear: "a woman at genetic risk should feel empowered to remove both breasts as a way to prevent the disease" (Grady, Parker-Pope & Belluck, 2013, para 2). On March 24th, 2015, Jolie followed up on her original editorial to reveal that she had subsequently also undergone removal of her ovaries and fallopian tubes to reduce her risk of developing ovarian cancer. Angelina Jolie, it appears, has opted to manage her genetic breast/ovarian cancer risk through RRS and she stated that she felt empowered by her decision. This decision is in keeping with Western medical discourse and identifies Jolie as a sensible woman who has acted appropriately by forfeiting her breast and ovaries to protect her health, her

life and her family. However, some women have a different experience: those women's experiences are the focus of this study.

CHAPTER 1: INTRODUCTION

“Everyone who is born holds dual citizenship in the kingdom of the well and the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, least for a spell, to identify ourselves as citizens of that other place.”

(Sontag, 1978, p. 3).

Foreword

This research is broadly concerned with the decision to say no to risk reducing surgery (RRS) for hereditary breast/ovarian cancer (HBOC). Modern Western medicine has led the increasing emphasis on genetic testing for many human ailments including HBOC (Conrad, 2001). Recognition of a genetic component to breast/ovarian cancer development has fuelled a public demand for information, reassurance and genetic testing (Chustecka, 2014) which has in turn led to an increasing number of women being offered RRS to remove healthy breasts and ovaries in order to reduce the risk of future disease (Stratton & Rahman, 2008).

The focus of this study are women who have been identified with carrying a genetic mutation which predisposes breast/ovarian cancer development and who have been offered but said no to RRS. For ease of writing the term ‘high risk’ is used to refer to women who carry these mutations. The aim of this study was to explore the experiences of high risk women who said no to RRS, and to illuminate an understanding of why these women made what appeared to be *anti-health* decisions in the context of modern Western medicine. The influence of dominant medical and sexual discourses is considered, as it is argued such communal discourses influence perceptions of women and women’s experiences in Western society and the resulting decisions they make with regards to RRS.

This study is timely in light of growing public and professional interest on genetic causes of disease and subsequent management of pre-disease 'patients'. This interest was palpably exposed in 2013 following revelations one of the world's most famous women had undergone surgical removal of her healthy breasts because of a genetic predisposition to breast/ovarian cancer. The resulting media coverage catapulted genetic testing and RRS into the public domain and sparked extensive debate on the rights and wrongs of what is arguably extreme preventative medicine.

Introduction

My interest in the topic of this study dates back to the early 1990s whilst working as a Breast Care Nurse Specialist. In my clinical practice, I primarily dealt with women undergoing surgical and medical interventions for breast cancer. At this time, women who attended the Breast Clinic because they had a family history of breast cancer, the so-called 'worried well', were managed ad hoc as there were no clinical guidelines which outlined best practice for these women. Their management inevitably involved a clinical breast examination, mammography, 'reassurance' and discharge from the clinic with no follow up. This changed in the early 00s when clinical testing for genetic breast cancer became widely available. The 'worried well' became 'presymptomatic patients' and guidelines were developed which outlined how such women should be counselled, screened and managed. I worked with many women who had a family history of breast/ovarian cancer and witnessed first-hand the anxiety, fear and distress which accompanied their situation. Despite genetic counselling and risk estimation information, for some of these women, their perceived reality involved a frightening choice: amputate their breasts and ovaries or develop cancer. It was my work with these women which ignited my interest in cancer genetics and propelled an interest in developing ways of supporting high risk women through their difficult journey, culminating in this dissertation.

Contextualising the research

Continuing advances in molecular biology, health technologies and imaging have changed the landscape of Western medicine as the quest for the ever-earlier detection of disease continues (Moynihan, Doust, & Henry, 2012). This is exemplified by the Human Genome Project (HGP) which began in 1990 and aimed to unearth and understand the genetic makeup of the human species (National Institutes of Health, (NIH), 2010). The primary goal of the HGP was to determine the sequence of chemical base pairs which make up Deoxyribose Nucleic Acid (DNA) and to identify and map the approximately 25,000 genes of the human genome from both a physical and functional standpoint. This map would reveal everything which is genetically determined about an individual's life: their genetic blueprint. This blueprint could be used to identify an individual's susceptibility to certain disease conditions and inform specifically tailored strategies for the diagnosis, treatment and prevention of disease (Jenkins & Collins, 2003). The human genome sequence was eventually completed in April 2003 and more than 1800 genes implicated in the development of a number of diseases have been discovered (NIH, 2010).

The sequencing of the human genome led to the identification of two genes (BRCA1 and BRCA2) which are implicated in the development of up to 10% of all breast (Apostolou & Fostira, 2013) and ovarian (Prat, Ribe & Gallardo, 2005) cancers. Deleterious mutations in these genes confer a significantly elevated lifetime risk of developing breast and ovarian cancer (Rebbeck, Kauff & Domcheck, 2009), although debate exists as to the most accurate risk estimation (National Cancer Institute (NCI), 2013). The discovery of, and subsequent clinical testing of these genes implies the generation of diagnoses on the basis of risk rather than causality (Webster, 2002) leading to a subset of high risk patients who have no symptoms of disease but who *may* develop cancer. Genetic testing represents a shift from a diagnostic model of medicine to a more prognostic-preventive model increasingly concerned with future

health (Paul, Banerjee & Michl, 2014). Whilst strong evidence supports a link between certain gene mutations and the development of cancer (Apostolou & Fostira, 2013), the tendency to treat genetic risk as disease in itself (Conrad, 2007) means people who carry BRCA1/2 mutations are essentially marked for cancer. Genetic testing thus has the potential to cause harm by revealing variations in genetic make-up which are associated with certain diseases, but which may never cause a threat to health (Faulkner, 2012; Melzer & Zimmerman, 2002).

Medical interventions to manage high risk women range from surveillance strategies to RRS and chemoprevention (National Institute for Health and Care Excellence (NICE), 2013). RRS does not entirely negate risk (Kraus & Adlard, 2013), however there is conclusive evidence Risk Reducing Mastectomy (RRM) and Risk Reducing Salpingo-oophorectomy (RRSO) significantly reduce the risk of developing breast and ovarian cancer in BRCA1/2 mutation carriers (Kraus & Adlard, 2013; Lostumbo, Carbine & Wallace, 2010). Therefore, although overall risk is lowered, cancer development following surgical removal of the breasts and ovaries can and does occur (Lostumbo et al., 2010). This means some women who have their healthy breasts and ovaries removed will still go on to develop cancer which adds to the complexity of the decision making around risk calculation and RRS. Additionally, although RRS reduces disease incidence in high risk populations, evidence to support a survival benefit is weak (Neuburger, MacNeill, Jeevan, van der Meulen & Cromwell, 2013) because should a woman develop cancer, she may be cured by conventional treatments. Therefore, located within the myriad of molecular and genetic discoveries are a group of women for whom technological advancements have raised many questions which cannot yet be resolutely answered. This is an important area of health research as the increasing number of women experiencing complex psychological issues as a result of being identified at high risk of cancer is well recognised (Eijzenaga, Hahn, Aaronson, Kluijt & Bleiker, 2014; Lerman, Croyle,

Tercyak & Hamann, 2002) and women owing BRCA1/2 mutations experience significant levels of emotional distress and anxiety (McLamara, 2013). This is not surprising given cancer remains the most feared of diseases (Vrinten, van Jaarsveld, Waller, Wagner & Wardle, 2014) and is surrounded by a discourse of fear and terror (Harrington, 2012).

The need for research

In an ever more technical world, advancements in medical technologies mean problems of a biological or pathological nature are increasingly able to be resolved, yet a corresponding efficacy in solving social and ethical dilemmas created by such advancements has yet to be achieved (Paul et al., 2014). In relation to HBOC, clinical advancements in the field of genetics have changed the landscape of the management of high risk women yet research on the impacts of such advancements is comparatively limited.

In 2013 in the UK, NICE published updated clinical guidelines for the classification, care and management of familial breast/ovarian cancer. The Guideline Development Group noted, with concern, the relative paucity of evidence upon which to base recommendations in many areas covered by the guidance. An overall increase in research on all aspects of HBOC was recommended. Similarly, a Cochrane Review on cancer genetic risk assessment in familial breast cancer (Hilgart, Coles & Iredale, 2012) concluded that more research on peoples' experience of the cancer genetics journey was needed, including decision making with regard to the uptake of preventative measures such as RRS. Of particular note, the authors' emphasised research on the impact of testing on those identified as high risk as an important area for further research, again highlighting the need for studies to explore women's experiences of being identified as owning a cancer predisposing gene fault.

This study addresses an important area of concern in contemporary health care: the care of people with presymptomatic conditions. The expansion of genetics in medicine has led to the identification of an increasing number of women as high risk of developing breast and/or ovarian cancer. In keeping with clinical guidelines, women identified as high risk of developing cancer will be required to make a decision as to whether to have their healthy breasts and/or ovaries surgically removed to prevent cancer (Eijzenga et al., 2014; Fuller & Anderson, 2006).

Public and professional interest in genetic testing continues to grow (Chustecka, 2014; Paul et al., 2014) and thresholds for genetic testing for breast/ovarian cancer have lowered (NICE, 2013) pre-empting an increase in RRS (Semple et al., 2013). An understanding of the needs of these women has yet to be obtained and they face a complex and, at times, difficult and distressing journey (Mahon, 2011; McLamara, 2013).

The growing dialogue on breast/ovarian cancer predisposition is reflected in the coining of the term 'previvor' in 2000. The origin of the term is attributed to the American-based non-profit organisation FORCE (Facing Our Risk of Cancer Empowered) and the term 'previvor' is now a registered trademark of the organisation. A 'previvor' is someone who does not have cancer but has a genetic predisposition to developing cancer (Mahon, 2011): a pre-survivor (Cruz, 2007). The word was described by Time magazine as being in the top 10 buzzwords for 2007 (Cruz, 2007) and its seemingly increasing importance reflected in the United States of America (USA) Congress supporting the designation of September 29th 2010 as 'National Previvor Day' (US Government, 2010). Although the concept of 'previvorship' is not the focus of this research, it none-the-less highlights the increasing prominence of HBOC in the public discourse. It is also interesting to note that the use of the term is now entering the professional discourse on hereditary breast/ovarian cancer (Hoskins,

Roy & Greene, 2012; Mahon, 2011; Pirzadeh, 2012; Tercyak, Mays, DeMarco, Sharff & Friedman, 2011). Use of the term 'previvor' is not without controversy (Oransky, 2012) and the 'previvorship' concept in health care research highlights how public and professional discourses can influence each other in contemporary health care. Moreover, the concept of previvorship reveals further evidence of medicalisation in health care (Oransky, 2012), in this case, the medicalisation of the risk of disease.

Scholars have increasingly commented on medicalisation within Western culture, whereby aspects of human life come to be considered as medical problems (Maturio, 2012) which can then be reduced or cured by medical interventions (Conrad, 2001, 2005). In this study, it is argued that women and their bodies and breasts are medicalised as a result of social, cultural and moral attitudes concerning the breasts and breast/ovarian cancer genetics. The medicalisation of women's breasts and the medicalisation of the risk of breast/ovarian cancer have implications for the ways in which women experience being diagnosed with a genetic predisposition to developing cancer, and to the subsequent decisions they make about their care. Medicalisation then constructs the breasts and ovaries of high risk women as faulty and is supported by a medical discourse which seeks to deal with the risk of cancer through various interventions on the body.

Biomedicine is the dominant Western medical discourse (Lane, 2014). Biomedicine is an organ-based approach to medicine which focuses on disease mechanisms (Lane, 2014) and is underpinned by the conviction that humans are biological organisms understood by the examination of constituent parts using the empirical scientific methods (Mehta, 2011). Accordingly, disease is a result of identifiable causes, located within the individual and best attended to by corrective surgical and pharmacological interventions (Filc, 2004; Mehta, 2011). The discourse of Western biomedicine is legitimised by its historical status and affiliation with scientific

disciplines (Davis, 2008). The biomedical model is helpful for those affected by disease as it is in the main, effective in diagnosing and treating disease (Lane, 2014). However, recognition of the impact of societal and cultural forces on the development, treatment and meaning of illness and disease is limited within this model (Davis, 2008; Filc, 2004; Lane, 2014). Thus the biomedical model is challenged by those who claim disease is a phenomenon with a biological component but also entails social stigmas and labels which require the individual to construct an identity which takes account of the illness (Davis, 2008). Hence the biological cannot be separated from the social and personal aspects of disease (Lane, 2014). This is particularly important in relation to cancer given the discourse of fear and terror (Harrington, 2012) within which cancer is enmeshed. Despite this, there is a paucity of research focussed on understanding why some people refuse conventional therapeutic interventions for managing cancer within the context of Western medical discourse (Citrin, Bloom, Grutsch, Mortensen & Lis, 2012; Frenkel, 2013; Verhoef, Rose, White & Balneaves, 2008).

This study concerns the experiences of high risk women who say no to RRS despite its emergence as the principle primary intervention for reducing breast/ovarian cancer risk (Ingham et al., 2013) and clinical guidance that surgery be offered to all high risk women (Cancer Australia, 2011; NICE, 2013). It is contended that the women in this study rejected the conventional therapeutic approach despite being at high risk of developing cancer. Davis (2008) notes that, all individuals are essentially 'at risk' of illness, disease or harm simply by being alive although for the majority this risk is tolerable and resides in the background of the person's life. However, being identified as having a genetic predisposition to cancer conveys inevitability about cancer development (Crabb, 2006) and brings this risk into the foreground of life (Davis, 2008).

What then for the woman with a genetic predisposition to breast/ovarian cancer facing RRS to remove her still healthy breasts and/or ovaries? These presymptomatic women live in a society where cancer seems omnipresent and remains the most feared (Vrinten et al., 2014) and stigmatised of diseases (Clarke & Everest, 2006) and where breast and ovarian cancer remain leading causes of death (Australian Institute of Health and Welfare (AIHW), 2012; World Health Organisation (WHO), 2009). These women have been informed they are genetically predisposed to developing breast and/or ovarian cancer as a result of genetic testing, yet medical science cannot prevent cancer, nor can any guarantee be given of avoiding cancer, even following removal of the breasts/ovaries. There is an assumption women at risk of cancer will engage in preventative strategies as they are the only sensible course of action (Davis, 2008). How then do we understand those who reject the conventional within modern Western medicine and make what appear to be 'anti-health' decisions regarding avoiding cancer? This is the juxtaposition women with a genetic predisposition to developing breast/ovarian cancer face: although still healthy, these women are being asked to undergo surgical removal of their organs.

The predicament of high risk women offered RRS is further complicated by the symbolisation of the breast, and to a lesser extent the ovary, as a defining part of the female form. Davis (2008) notes the female breast is an icon of the private individual self and the culturally shaped public self. The meaning attached to, and the resulting folklore surrounding the female breast is in many ways highlighted by the acceptance of cosmetic breast augmentation in Western society which reifies the notion of the perfect breast (Filc, 2004). Further, Filc (2004) argues the undertaking of a potentially risky surgical procedure in order to perfect breasts which do not conform to the socially and culturally constructed ideal is another example of the hegemony of Western medical discourse and resulting medicalisation of non-medical issues.

Justification for the approach taken

A growing body of literature exists on genetic breast/ovarian cancer and the merits of various therapeutic interventions and responses to such interventions. The focus of research in the main has been concerned with efficacy of different risk reducing interventions and the associated potential benefits and harms. There is an absence of research which investigates the social, cultural and historical contexts in which decision making around HBOC is made. The majority of studies, to date, have used standardised psychometric instruments to assess the impact of risk, risk calculation and risk reducing interventions on women at risk of developing HBOC. Such instruments utilise pre-determined criteria for measuring women's responses, attitudes, beliefs and so forth, which arguably leads the research from the standpoint of the researcher and assumes what the women's responses might be beforehand.

The focus has tended to be on identification and measurement of variables which may influence or predict decision-making in high risk women. A challenge inherent in this type of approach is attempting to make real-life, personal experience fit into preconceived, so-called expert opinion on what is important. It may be contended that such approaches fail to take account of the entire range of influences on making health-related decisions, conscious and sub-conscious, known and unknown, to which women in Western society are subject. Moreover, despite the importance attached to women's breasts and ovaries in Western society, little consideration has been given to the ways dominant societal discourses impact on women's experiences and decision making in relation to RRS. What is lacking from this body of research is an understanding of the experience of saying no to RRS from the perspective of high risk women based on the material and social conditions of their everyday lives.

The approach taken in this study sought to explore the experiences of high risk women who said no to RRS. Further, by giving voice to this group of women, this

study revealed an understanding of the public and private folklore shared by these women, of a life trajectory compounded by living with a cancer predisposition. This voice was heard within the context of personal, social, cultural and historical influences. Illuminating an understanding of this will help inform and influence counselling of high risk women.

A qualitative approach which combined Denzin's (1989) interpretive biography with Dolby-Stahl's (1985) literary folkloristic methodology was used as a method through which the women's stories could be gathered, read and interpreted. Each woman's experiences were valued and worthy of investigation. This approach is particularly suited to understanding an individual's experiences at key moments in their lives (Surr, 2006) such as women who had been told they are at high risk of developing cancer but said no to RRS. Dolby-Stahl's (1985) literary folkloristic methodology was used to unravel and interpret these women's stories and to determine the private folklore of this group of women. Without such an understanding, it is difficult for health care providers to justify approaches taken to support and care for such women. Without understanding it is argued, there can be no real knowledge.

Significance of the research

The significance of this study is the generation of new knowledge related to the experiences of women who say no to RRS following a mutation-positive genetic test result. The study questions taken-for-granted assumptions of how women who are formally acknowledged to be high risk of developing cancer make the decision to take no action. By stimulating debate and providing future directions for research on how high risk women come to say no to RRS, this study opens up possibilities for critically examining current care practises of high risk women and has implications for how information is presented and communicated to high risk women. The knowledge gained will assist in the care of women through the development of information and

support strategies which are relevant and meaningful to high risk women considering RRS. This knowledge will inform health professionals, educators and policy makers of new ways to consider the management of presymptomatic genetic testing to transform disease prevention and develop targeted interventions.

Purpose of the research

The purpose of this study was to explore the experiences of women who said no to RRS following a mutation-positive genetic test result.

The aims of the study were:

1. To explore the experiences of high risk women who say no to RRS.
2. To create new knowledge regarding the refusal of RRS in high risk women within the framework of Western medical discourse.
3. To add to the current understanding of how high risk women come to say no to RRS and make recommendations for the care, counselling and support of such women.

Chapter summary and overview of chapters to come

This chapter introduced the issues of concern in this study and outlined the purpose and aims of the research. Justification for the approach taken has been presented and the need for and significance of this research is explained. Chapter 2 comprises a review of pertinent literature in order to contextualise the analysis which follows in subsequent chapters. In Chapter 3 the methodological approach taken is described and justified. Chapter 4 outlines the steps taken in the conduct of the study and provides a comprehensive overview of the literary theories used to interpret the participants' experiences. Chapter 5 introduces the participants, describes how intimacy was established presents the participants' biographical timelines with family histories and epiphany moments. Chapter 6 is the analytic chapter in which the

women's experiences and influences on their decision to say no to RRS are interpreted through the three literary theory lenses. The thesis concludes with Chapter 7 which draws together the key findings from the study, considers implications for clinical practice and further research and presents the researchers' reflexive account.

To conclude this section, it is important to stress it is not the intention of this thesis to criticise genuine attempts to reduce the harm caused by breast/ovarian cancer nor to deny the potential positive impact genetic testing and RRS can have on the lives of some high risk women. Likewise, any critique is not directed at the women making difficult choices when faced with the prospect of hereditary breast/ovarian cancer. Rather, the aim is to problematise the dominant discourse on genetic testing and RRS which constructs such interventions as universally and inherently *a good thing*. This thesis critiques ways in which women at risk of cancer and their choices are represented in discourse. It presents alternate meanings attached to the experience of being identified as high risk of developing breast/ovarian and in doing so, generates broader discourses which construct how HBOC is talked about and ultimately experienced. If medicine is to abide by its founding principle to 'first do no harm', then any medical advancement which does appear to cause harm in some women is worthy of exposure and investigation.

CHAPTER 2: LITERATURE REVIEW

Introduction

The overall purpose of this literature review was to provide an overview of the issues of concern in this study in order to contextualise the analysis which follows in later chapters. The approach taken in this study contends that a communal folklore surrounding breast/ovarian cancer exists. This communal folklore is underpinned by dominant modes of thinking which consent to or censure certain ways of being and acting when faced with the risk of cancer. In the dominant medical discourse, women identified as high risk of developing breast/ovarian cancer are able to circumvent their genetic destiny through the surgical removal of their still-healthy breasts and ovaries. Medical discourse fails to articulate an understanding of other dominant gendered discourses which shape the experiences and lives of high risk women in Western society because ideologies of treatment for risk take precedence. The decision of women identified as high risk of developing breast/ovarian cancer to say no to RRS is argued to be 'anti-health' within current Western medical discourse however as will be discussed, this decision makes sense when it is made within other dominant discourses. This is the paradox faced by high risk women.

At this point, attention is drawn to the rapidly changing landscape that is HBOC. The introduction to this thesis highlighted how HBOC has been catapulted into the public arena in the last two years as a result of widespread media coverage of Angelina Jolie's risk reducing surgery to remove her breasts and ovaries. Professional discourse on the management of HBOC is likewise dynamic with the most recent UK guidelines published as recently as July 2013 (NICE, 2013). These guidelines in themselves reveal not only is the medical management of HBOC currently unstable, but also that much remains unknown about how best to manage HBOC in terms of clinical and psychosocial indicators since gaps exist in the evidence base to support

current clinical recommendations. This is not surprising when one considers it is not yet 20 years since the two key genes implicated in the development of HBOC were mapped, isolated and subjected to extensive scrutiny. Consequently widespread genetic testing has been available for a relatively short period of time therefore research around risk reducing interventions is somewhat limited in comparison to other areas of cancer care. The nursing research in relation to the care and management of women facing HBOC is an emergent area therefore gaps also existed in the literature in relation to sourcing relevant sources to support this research. This meant it was necessary at times to extrapolate from wider literature which related to women diagnosed with breast and/or ovarian cancer. This in itself was not problematic and as is seen, it is evidence of dominant yet dynamic discourses on risk, genetics and cancer which expose women with no disease to a number of influences, ideologies and impacts which are also faced by women with breast/ovarian cancer.

Search parameters

The literature search commenced in 2009 using several electronic databases: MEDLINE, Medline In Process and Other Non-Indexed Citations, MEDLINE Daily Update, CINAHL, CancerLit, EMBASE, Cochrane Library, PsycInfo, Web of Science and Journals@OVID. The search was limited to articles written in English and was updated on a continual basis. The generic internet search engines 'Google' (<http://www.google.co.uk>) and 'Google Scholar' (<https://scholar.google.co.uk/>) were also utilised as potential sources of literature. Government and health organisation websites were accessed and a hand search conducted of the reference lists of papers and documents retrieved for additional literature. Literature over 10 years old was included if it was of a seminal nature and/or written by prominent authors in the field.

A number of key search words were utilised in the search which reflected the key areas of concern and included: familial, genes, genetic, genetic testing, screening,

hereditary, breast, ovarian, cancer, predisposition, susceptibility, risk, high risk, cancer risk, communicating risk, BRCA, mastectomy, oophorectomy, prophylactic, preventative, risk reducing, surgery, Western, medical, medicine, discourse, women, female, femininity, society, ideology and medicalisation. Literature pertaining to the method was also extensively searched using the same process and involved the key search words: interpretive biography, biographical, Marxism, Marxist, feminist, feminism, Foucault, Foucauldian, literary theory, literary criticism, folklore, life stories, personal experience narratives and narrative analysis.

A considerable body of literature was found in relation to risk reducing interventions for high risk women. Given the focus of the research were high risk women who say no to RRS within the context of Western medical discourse, this study was contextualised within several key areas of literature. First, literature relating to breast/ovarian cancer genetics, risk estimation and genetic testing was reviewed. The focus of the review then narrowed to draw upon literature related specifically to risk reducing interventions and the physical and psychosocial impacts of RRS. The review concludes with a discussion of the concepts of medicalisation and risk and how these concepts have contributed to contemporary understandings of breast/ovarian cancer. Literature pertaining to the method is discussed in Chapters 3 and 4.

Cancer genetics

The term 'cancer' refers to a number of diseases caused by the uncontrolled division and replication of abnormal cells in a part of the body. In normal cells, growth and division is a carefully regulated process which depends on the interaction of a number of regulatory factors contained within the genetic material of the cell, the DNA (deoxyribonucleic acid) (Corner, 2008). Homeostasis is maintained when there is a balance between cell proliferation and cell death. Cancer results from a series of genetic alterations which lead to a progressive disordering of the normal cell control

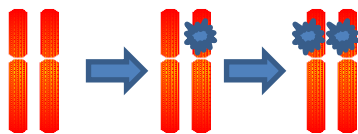
mechanisms, a multi-step process known as carcinogenesis (Corner, 2008) the process of which is influenced by a number of genetic, epigenetic and non-genetic factors (Van Gerpen, 2007).

All cancers have a genetic basis, that is, they occur as a result of mutations in genes. Genes are sub-units of DNA and are formed as 23 pairs of chromosomes; therefore, cells contain two copies of each gene (Cancer Research UK, 2014). The majority of cancers are caused by acquired, chance mutations through an individual's exposure to endogenous and exogenous DNA-damaging elements (Stratton, 2011) such as viruses, radiation, carcinogenic agents and naturally occurring random mutations which corrupt DNA. These are known as somatic mutations and are present only in the damaged cells, therefore these mutations cannot be passed to offspring (Arden-Jones, Thomas, Docherty & Eles, 2008). Multiple mutations which corrupt both copies of a gene are necessary before loss of cellular control occurs. Whole genome-sequencing studies have shown between 1000 and 10,000 somatic mutations to be present in most adult solid tumours (Baird & Caldas, 2013).

In contrast, inherited mutations, such as those associated with HBOC, are germline mutations which means the mutation is present in the sex chromosomes (of the sperm and ova) hence can be passed on to offspring (Arden-Jones et al., 2008). During conception, the developing zygote randomly inherits a single copy of every chromosome from each parent. Since there are two copies of each chromosome, the child could inherit the faulty (mutated) copy or the normal copy. If either parent has a germline mutation, each child conceived has a 50:50 chance of inheriting that mutation (Cancer Research UK, 2014). Additionally, because the mutation is in the germline, it will be present every DNA-containing cell in the individual's body (Arden-Jones et al., 2008). Germline mutations confer increased susceptibility to cancer through various mechanisms including directly promoting cell growth, altering the rate

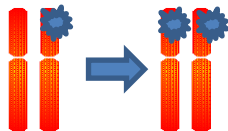
of mutation in somatic cells and loss of modulating harmful effects of carcinogen exposure (Stratton, 2011). Cancer is more likely if a mutated version of the chromosome/gene is inherited because the person already has one faulty copy of a gene therefore requires less subsequent corrupting events to develop cancer, as outlined in the diagram below.

Sporadic cancer: mutation on both copies of gene acquired over time



Uncontrolled cell proliferation leading to cancer.

Inherited cancer: one mutated copy inherited and already present



Uncontrolled cell proliferation leading to cancer.

Figure 1: Sporadic versus inherited mutation gene corruption.

Breast/ovarian cancer predisposition

Breast cancer is the most common cancer diagnosed in women and accounts for almost 25% of all female cancer (NICE, 2013). The worldwide overall lifetime risk of women developing breast cancer remains approximately 1 in 10 (NCI, 2013). In Western countries, the risk is higher. Women in the United Kingdom (UK) and Australia have a 1 in 8 chance of developing breast cancer before the age of 85 (AIHW, 2012). Sixty-six percent of deaths from breast cancer occur in Western countries, although breast cancer incidence and mortality continues to rise in developing countries (WHO, 2008).

The worldwide overall lifetime risk of a woman developing ovarian cancer is approximately 1 in 71 or 1.4% (NCI, 2013). The risk in Australia is comparable at 1 in 77 (AIHW, 2010). In the United Kingdom however, the risk is higher at 1 in 54 (Cancer Research UK, 2012). Reasons for this are believed to be a higher prevalence of known risk factors such as older age, high fat diet and high alcohol consumption, fewer pregnancies/children and higher usage of hormone replacement therapy (Cancer Research UK, 2012).

The clustering of breast cancer in families has been recognised for several hundred years, although it was not until the mid-20th century when more systematic attempts to document 'cancer families' led to the hypothesis some breast cancers may have a strong hereditary element (Easton, Antonio & Thompson, 2008). Epidemiological studies identified first-degree female relatives of women with breast or ovarian cancer were more likely to develop the disease than the general population, and this was more likely to be a result of genetic predisposition rather than environmental or behavioural factors (Stratton & Rahman, 2008). It is now estimated up to 10% of breast (Apostolou & Fostira, 2013) and ovarian (Rosenthal et al., 2012) cancers are hereditary, that is, attributable to deleterious mutations in the genetic material passed on from parents to offspring. Family history is considered the most significant risk factor for ovarian cancer development (Easton et al., 2008; Prat et al., 2005) and one of the most important for breast cancer development (Antoniou & Easton, 2006; NICE, 2013).

Genetic mutations and breast/ovarian cancer predisposition

Gene sequencing technology has identified some of the genes implicated in susceptibility to breast/ovarian cancer development (Antoniou & Easton, 2006; NICE 2013). These include the BRCA1, BRCA2, CHEK2, TP53, and PTEN genes although mutations in the latter three are rare compared with BRCA1 and BRCA2 mutations

(Walsh et al., 2006). Thus, **BR**east **C**Ancer1 (**breast cancer** susceptibility gene 1) and **BR**east **C**Ancer2 (**breast cancer** susceptibility gene 2), are considered the most important cancer predisposition genes (Bradbury & Olopade, 2007) and the majority of women identified as high risk will carry a deleterious mutation in one of these genes (NICE, 2013). BRCA gene mutations are also associated with a higher risk of other cancers including cancers of the head, neck and skin (Narod & Offit, 2005), pancreas, uterus and biliary system (Thompson & Easton, 2001) and fallopian tubes and peritoneum (Casey et al., 2005).

Identified in the mid 1990's, BRCA1 and BRCA2 are genes located on chromosomes 17 and 13 respectively. BRCA1 and BRCA2 are tumour suppressor genes involved in various cell regulation functions including DNA repair, cell cycle regulation and apoptosis (the process of programmed cell death) (Yoshida & Miki, 2004). Tumour suppressor genes prevent neoplastic development by repressing or inhibiting cell division and growth thus maintaining homeostasis. BRCA1 and BRCA2 mutations therefore are not oncogenes, that is, they do not cause cancer. Rather their inability to function normally increases the likelihood of malignant transformation in cells.

Thousands of different disease-associated mutations in the BRCA1/2 genes have so far been identified although much fewer are known to be deleterious (Antoniou & Easton, 2006; Borg et al., 2010). It is estimated approximately 0.25% of the general population will carry BRCA1/2 mutations (NCI, 2014). This figure rises to 2% for women with breast cancer, 5% for men with breast cancer and 10-15% for women with ovarian cancer. Rates in the Ashkenazi Jewish population are higher at 2.5% for the general population, 10% for women with breast cancer, 19% for men with breast cancer and 36-41% for women with ovarian cancer (NCI, 2014). The higher incidence of BRCA mutations in people of Ashkenazi Jewish descent is a result of what is termed the 'founder effect'. This occurs when a new population is established by a

small group of people (founders) who are culturally and/or geographically isolated, leading to inbreeding and a loss of genetic variation (Ferla et al., 2007). Founder mutations are those present in the DNA of the founders of the new population which can be passed down to other generations. Three founder mutations (two in BRCA1 and one in BRCA2) are known to be present in the Ashkenazi Jew population accounting for this particular group's higher incidence of inherited breast and ovarian cancer (Ferla et al., 2007).

Transmission of BRCA1/2 mutations occurs in an autosomal dominant pattern which means inheriting only one copy of the mutated gene increases cancer risk (NCI, 2014). Each child of a carrier parent has a 50% chance of inheriting the mutated copy therefore both mothers and fathers can transmit a BRCA1 or BRCA2 mutation to sons and daughters.

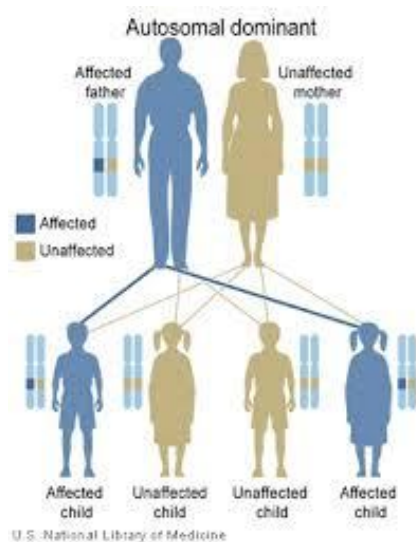


Figure 2: Autosomal dominant inheritance.*

(*Attribution: By U.S. National Library of Medicine (Genetics Home Reference) [Public domain], via Wikimedia Commons)

BRCA1/2 mutations and breast/ovarian cancer risk estimation

Germline mutations in BRCA1 and BRCA2 confer higher risks of developing breast and ovarian cancer although penetrance, the likelihood of a mutation-carrier

manifesting the disease, is incomplete (Lessick, 2007) therefore not all mutation carriers will go on to develop the disease. Since there is no test or intervention which can accurately predict who will go on to develop breast/ovarian cancer, many women will have RRS needlessly (Lostumbo et al., 2010) because they would never have developed cancer. Thus the genetic pathway associated with breast/ovarian cancer gene mutations differs to that of other single disorder/high penetrance genes such as those associated with Huntington's disease where penetrance is almost 100% (Melzer & Zimmerman, 2002).

Attempts have been made to estimate the cancer risk conferred by BRCA1/2 mutations. The majority of studies have identified BRCA1 mutations as conferring greater risk than BRCA2 (NCI, 2014). Three large meta-analyses have been conducted although in the most recent (van der Kolk et al., 2010) a greater risk for breast cancer was associated with BRCA2 mutations. van der Kolk et al. (2010) acknowledged the BRCA2 breast cancer risk reported was higher than most other published data, but reasons for this were not fully articulated. Risk estimates by mutation and cancer type are summarised in Table 1 below.

Table 1: Risk estimates by mutation and cancer type

Authors	Cancer type	BRCA1 mutation risk by age 70 years	BRCA2 mutation risk by age 70 years
van der Kolk et al. (2010)	Breast	71.4% (95% CI, 67.2 - 82.4%)	87.5% (95% CI, 82.4 - 92.6%)
van der Kolk et al. (2010)	Ovarian	58.9% (95% CI, 53.5 - 64.3%)	34.5% (95% CI, 25.0 - 44.0%)
Chen & Parmigiani (2007)	Breast	57% (95% CI, 47% - 66%)	49% (95% CI, 40% - 57%)
Chen & Parmigiani (2007)	Ovarian	40% (95% CI, 35% - 46%)	18% (95% CI, 13% - 23%)
Antoniou et al. (2003)	Breast	65% (95% CI, 44 - 78%)	45% (95% CI, 31 - 56%)
Antoniou et al. (2003)	Ovarian	39% (95% CI, 18 - 54%).	11% (95% CI, 2.4 - 19%).

Cancers arising as a result of BRCA1/2 mutations are also associated with a number of negative biological characteristics in comparison with sporadically occurring cancers. These include younger age at diagnosis, (Salhab, Bismohun & Mokbel, 2010), more aggressive disease (Kuhl, Kuhn & Schild, 2005; Zagouri et al., 2013), negative prognostic indicators such as oestrogen-receptor negative status (Calderon-Margalit, & Paltiel, 2004; Domcheck et al., 2010) and contralateral disease (Evans et al., 2013).

BRCA1/2 mutations are also associated with an increased risk of male breast cancer. Male breast cancer is rare and accounts for less than 1% of all breast cancer cases (Tai, Domchek, Parmigiani & Chen, 2007) and the general population risk of breast cancer in men is 0.1% (Berliner, Fay, Cummings, Burnett & Tillmanns, 2013). Increased rates of male breast cancer of 1.2% (Tai et al., 2007) and 4% (Ottini et al., 2003) have been reported in BRCA1 mutation carriers. The link with male breast cancer is more established for BRCA2 mutations (Weiss, Moysich, & Swede, 2005) with increased rates of 6.8% (Tai et al., 2007) and 5 – 10% (Institute of Cancer Research, (2015) reported.

Overall then, there is agreement owning a BRCA1/2 mutation confers an increased risk of breast and/or ovarian cancer but the magnitude of risk varies. Several factors are apparent which may explain this. Although gene mutations have been identified which appear to predispose cancer development, the exact mechanism by which this process occurs is not understood. Different BRCA1 and BRCA2 mutations are associated with varying degrees of penetrance (Njiaju & Olopade, 2012). For example, mutations in the central region of the BRCA1 gene confer lower breast cancer penetrance than mutations in other positions on the gene (Thompson & Easton, 2001). Available evidence also suggests breast/ovarian cancer risk is modified through various genetic, epigenetic and non-genetic factors which impact on

penetrance. Age at diagnosis of affected relative, cancer type in affected relative, parity, body mass index, exposure to endogenous hormones, age at menarche and menopause, early oophorectomy and breast density are believed to modify cancer risk in BRCA1/2 mutation carriers (Antoniou & Easton, 2006) and the general population (Easton, Antoniou & Thompson, 2008). A further complicating factor is that several known risk factors for breast cancer in particular also have a hereditary basis, for example, breast density and age at menarche/menopause (Easton et al., 2008). This means clusters of breast cancer may appear in families without a heritable gene mutation.

Accurate risk estimation in BRCA1/2 mutation carriers is also hampered because not all genes involved in cancer development have been identified or understood (Antoniou & Easton, 2006). It is estimated that BRCA1/2 mutations account for less than 5% of the total incidence of breast/ovarian cancer (Oldenburg, Meijers-Heijboer, Cornelisse & Devilee, 2007) and no more than 25% of familial breast/ovarian cancer (Antoniou & Easton, 2006). There is general agreement many more cancer genetic susceptibility genes exist which have not been discovered (NCI, 2014; Oldenburg et al., 2007). Furthermore, the ways in which multiple genes modify cancer risk is not understood which further limits the effectiveness of risk estimation in mutation carriers (Antoniou & Easton, 2006).

The model used to estimate cancer risk also impacts on the risk estimate obtained (Antoniou, Pharoah, Smith & Easton, 2004; NICE, 2013). A range of computational risk assessment models have been developed in attempts to quantify risk assessment for individuals with a breast/ovarian cancer family history (Bradbury & Olopade, 2007). The use of a particular model must be tailored to the individual's characteristics and family history, which must be similar to the study population upon which the model is based (NCI, 2014). Moreover, no model has been developed which takes account of

all cancer risk factors, ethnicity, and individual non-genetic risk factors (Bradbury & Olopade, 2007; NICE, 2013). Different models show variation in risk estimate for the same clinical scenario (NCI, 2014) therefore a degree of expertise is needed in choosing the most appropriate model(s) for calculating risk breast/ovarian cancer risk (Bradbury & Olopade, 2007). It is widely acknowledged current models of risk estimation are more accurate in determining population risk and are limited in their predictive ability for individual risk calculation (Antoniou & Easton, 2006; Bradbury & Olopade, 2007; NICE, 2013; Prado, Andrades & Parada, 2010).

Overall then, although understanding of breast/ovarian cancer genetics is increasing, much remains unknown about how breast/ovarian cancer develops in women who carry BRCA1 and BRCA2 mutations. Current interventional strategies for high risk women, including RRS, are based on risk estimations gained from mathematical models which are acknowledged as being limited in terms of predictive ability for individual risk calculation. Moreover, much of the information used in genetic counselling is based on uncertainty and probability (Emery, Murphy & Lucassen, 2000) rather than sureness and certitude. A Cochrane review on RRM for the prevention of breast cancer (Lostumbo et al., 2010) highlighted there was insufficient evidence regarding its effectiveness in reducing mortality in all but very high risk women and stated there was a risk of over-treatment for many women. Nonetheless, cancer prevention remains central to worldwide cancer control strategies and attempts to identify high risk individuals who may benefit (in terms of lowering risk) from aggressive risk reducing strategies remain a key feature of cancer medicine.

Genetic testing for breast/ovarian cancer predisposition

Clinical testing for BRCA1 and BRCA2 mutations became available in 1996 (Bonadies, Myer & Matloff, 2011) and now forms a standard part of HBOC management (NICE, 2013). Although the associated technology is now established,

the overall process is complex and uncertainty exists regarding who and when to test and the most accurate methods of estimating and communicating risk (NICE, 2013). Additionally, challenges exist in determining the accuracy of a family history. There may be poor communication between families, dates of diagnosis may be inaccurate or unknown and there may be missing information if relatives are deceased or estranged (Parker, London & Aronson, 2013). Malignancies of the pelvis and abdomen are commonly confused in families (NICE, 2013), for example, believing a cancer of the cervix or endometrium to be a cancer of the ovary or vice versa. Genetic testing is also prone to revealing incidental findings, or information which was not requested such a child conceived through an extra-marital affair or an adopted child (Greenbaum, 2013) hence people may withhold information or intentionally provide erroneous information (Parker et al., 2013). In cases where the family history is unclear or incomplete, it is necessary for clinicians to make decisions on testing locally on a case-by-case basis (NICE, 2013). It is evident therefore the genetic testing journey is varied and people's experiences will differ depending on their family and personal history and the geographical area in which their health care services are situated. Consequently, this section provides a general overview of genetic testing for illustration purposes but it may be individual experiences differ to those presented.

Genetic testing for BRCA1 and BRCA2 mutations in suspected HBOC families is a two-step process. The first step involves a mutation screen on the DNA (obtained through a blood sample) of an affected family member, that is, a living person diagnosed with breast or ovarian cancer. This is referred to as diagnostic testing (National Library of Medicine, 2013) and involves searching the affected person's DNA to identify a particular mutation on the BRCA1 or BRCA2 gene. If a deleterious gene mutation is identified, other unaffected family members can be tested for the presence of the mutation, a procedure known as predictive (or presymptomatic testing) (National Library of Medicine, 2013). If the mutation is found in the person's

DNA, they are classified as high risk and a personalised risk assessment can be generated. If on the other hand the person has not inherited the mutation, their risk is the same as the general population risk. A third outcome is the individual is found to own a variation of unknown (uncertain) significance (VUS) (Esplen & Bleiker, 2015). No robust clinical data is available to recommend a specific strategy for dealing with VUS therefore the clinical management of such individuals requires to be individualised according to family history and other personal risk factors (NCI, 2014).

Threshold for genetic testing

Genetic testing for cancer predisposition involves significant financial and human resources and has important implications for those tested, therefore guidance exists on when individuals should be offered a diagnostic or predictive test. NICE (2013) guidelines allow mutation screening on individuals where there is a 10% or greater likelihood of detecting a deleterious mutation. This figure is lower than the previous threshold of 20% set by NICE in 2006 therefore more people now meet the criteria for genetic testing.

The Manchester Scoring System (Evans et al., 2004) is the most frequently used empirical scoring system to estimate the likelihood of detecting a BRCA1/2 mutation in an individual's DNA (NICE, 2013). The score generated is dependent upon various criteria including the age at diagnosis of affected individuals, type of cancer, the presence of male breast cancer and/or multiple cancers in the family. A higher score equates with higher likelihood of a gene mutation being detected and therefore aids decision making on who is suitable for testing (Evans et al., 2004). In Australia, the Familial Risk Assessment - Breast and Ovarian Cancer (FRA-BOC) (Cancer Australia, 2011) is used to estimate an unaffected woman's risk of developing breast/ ovarian cancer and identify who should be referred to a specialist family cancer clinic for further assessment and testing. The process is presented diagrammatically below.

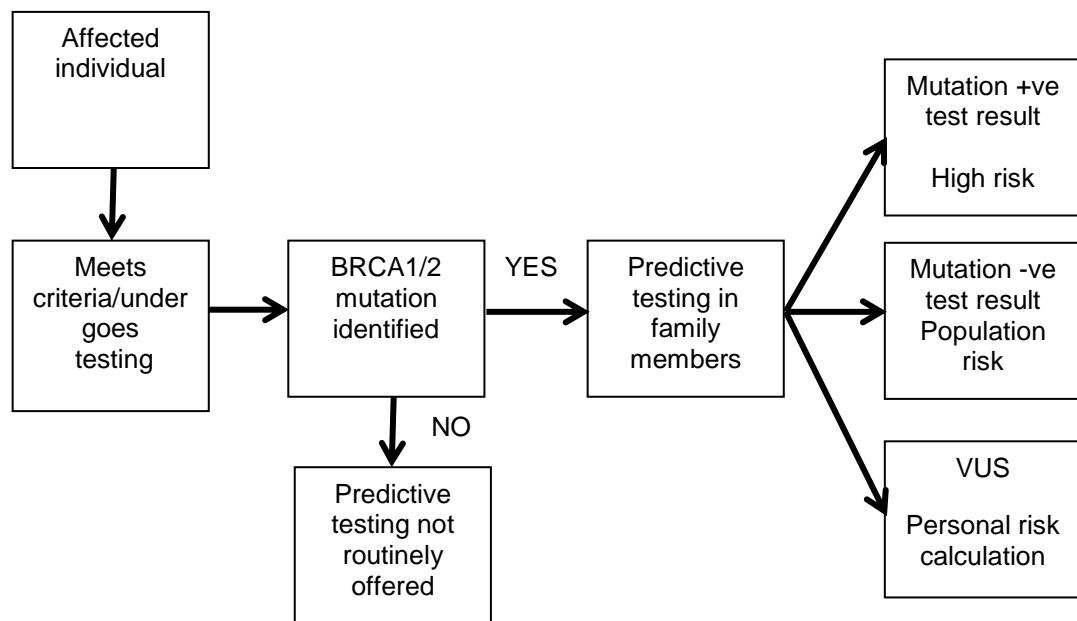


Figure 3: Genetic testing process.

Intervention strategies for women at high risk of developing breast/ovarian cancer

Genetic testing for breast/ovarian cancer predisposition is carried out on the premise it allows interventions aimed at reducing cancer morbidity and mortality (Esplen & Bleiker, 2015; Schwartz et al., 2012). Although there is an emerging literature on the benefits and drawbacks associated with risk reducing interventions, gaps exist in the evidence to support such strategies (NICE, 2013; Schwartz et al., 2012). This is not surprising when one considers BRCA1 and BRCA2 were only identified in 1996 therefore the evidence to date has been accumulated in a relatively short period of time. The implication of this is current guidance on management is likely to continue to be modified over coming years as new evidence emerges and preliminary research study findings are validated or not. Indeed the literature review for this study identified a rapidly changing medical and genetic landscape in relation to breast and ovarian cancer even over the relatively short study period.

Surveillance strategies

Surveillance strategies for high risk women are based on the premise early detection of disease potentially reduces cancer-related morbidity and mortality (NICE, 2013). A number of surveillance strategies have been implemented and evaluated in attempts to devise an optimal strategy for high risk individuals.

Breast examination

There is no evidence breast self-examination (BSE) or clinical breast examination (CBE) confers any survival benefit in high risk women (Horsman et al., 2007; NICE, 2013). Both procedures have been identified as potentially harmful (Koster & Gotzsche, 2003; NICE, 2013) as there can be an association with unnecessary biopsies, anxiety and false reassurance leading to delays in diagnosis should an interval cancer develop (Horsman et al., 2007). CBE however is recognised as potentially beneficial if undertaken by a skilled clinician in conjunction with other surveillance measures (Horsman et al., 2007; NICE, 2013). In keeping with health advice aimed at the general population, high risk women are encouraged to be 'breast aware' by knowing how their breasts look and feel and to seek medical advice if any changes or abnormalities become apparent (NICE, 2013).

Surveillance by imaging

Mammography and more recently magnetic resonance imaging (MRI) are the main surveillance methods for detecting breast cancer (NICE, 2013). The majority of published evidence relates to mammography owing to the relative recency of MRI screening. NICE (2013) recommend BRCA mutation carriers with no personal history of breast/ovarian cancer commence annual mammographic breast surveillance at age 40 years and annual MRI surveillance at age 20 years, although breast surveillance has been recommended elsewhere to commence as early as 25 – 30 years of age (de Gonzalez, Berg, Visvanathan, & Robson, 2009).

There is established evidence mammography reduces breast cancer mortality in the general population (Independent UK Panel on Breast Cancer Screening, 2012; Warner et al., 2011) but there is much uncertainty regarding absolute benefit in terms of lives saved and possible harms of screening (Independent UK Panel on Breast Cancer Screening, 2012). Similarly, mammography has become widely used in the high risk population although available evidence has yet to demonstrate the overall safety and efficacy of it (de Gonzalez, et al., 2009) and the impact on survival (Horsman et al., 2007; Schwartz et al., 2012).

Mammographic screening in BRCA mutation carriers poses particular challenges owing to breast and tumour biology, the age of the target population and the potential harms of mammography (Horsman et al., 2007; Kuhl et al., 2005; Zagouri et al., 2013). Breast density in pre-menopausal women makes mammography less sensitive and therefore less effective in detecting malignancy (Warner et al., 2008). There is the potential for harm because a dose-response relationship exists between ionising radiation and breast cancer development (Kuhl et al., 2005; Preston et al., 2009) therefore high risk women who commence mammographic surveillance at an earlier age will accumulate a greater lifetime exposure hence a greater risk of mammography-induced cancer (de Gonzalez, et al., 2009; Kuhl et al., 2005; Kurian, Sigal & Plevritis, 2010). Moreover, some deleterious BRCA mutations are associated with a reduction in capacity to repair DNA (Brennan, 2002; Kuhl et al., 2005) therefore the breasts of high risk women may be paradoxically more sensitive to the harmful effects of mammography (de Gonzalez et al., 2009; Kuhl et al., 2005; NICE, 2013).

Mammographic screening is also associated with increased psychological distress and anxiety and reduced quality of life (Kurian et al., 2010). Women may be falsely reassured by a 'clear' result and therefore neglect to report breast abnormalities which occur during the interval between scans (Griffiths, Bendelow, Green & Palmer, 2010).

False positive results can lead to unnecessary exploratory operations and increased biopsies (Hallowell, 1988; Kurian et al., 2010), whereas false negatives may result in malignancy being missed and delay diagnosis of cancer (Kurian et al., 2005).

Attempts have been made to address the potential drawbacks of mammographic surveillance through the implementation of MRI screening. MRI offers some benefits particularly in younger women as it is unaffected by breast density and does not use ionising radiation (Kuhl et al., 2005; Warner et al., 2008). MRI hence offers improved sensitivity over mammogram (Kuhl et al., 2005; NICE, 2013, Warner et al., 2008) but is less specific (Evans & Howell, 2007; Kuhl et al., 2005) particularly for invasive and in situ cancer (Kurian et al., 2005). Evidence suggests a combination of mammography and MRI may offer the most effective surveillance strategy in high risk women (Kuhl et al., 2005; Warner et al., 2008), but more data are required to determine the associated risks and benefits across a range of outcome indicators (Horsman et al., 2007; Schwartz et al., 2012).

No effective screening method for ovarian cancer exists (Chai et al., 2014; Domcheck et al., 2010). Ovarian surveillance for high risk women aims to detect tumours at sufficiently early stage to improve survival given the poor prognosis associated with late stage ovarian cancer (Evans et al., 2009). Surveillance utilising transvaginal ultrasound (TVU), (combined with serum CA125 testing) has been the most extensively investigated (Das & Bast, 2008). All evidence to date suggests annual TVU and/or serum CA125 monitoring has no impact on survival in high risk women (Das & Bast, 2008; Domcheck et al., 2010; Evans et al., 2009; Moyer, 2012) and the potential harms of screening have been highlighted as an area of concern (Moyer, 2012).

One of the largest studies to examine the safety and efficacy of ovarian surveillance in high risk women was the UK Familial Ovarian Cancer Screening Study (FOCSS) (Rosenthal et al., 2012). Phase 1 of the study of 3563 high risk women ended in 2010 and found screening in the year prior to a diagnosis of ovarian cancer reduced the incidence of late stage cancers but did not increase the incidence of early stage (stage 1) cancers. A non-significant trend to increased survival was found but this may have been a result of lead-time bias, that is, longer survival owing to earlier diagnosis rather than efficacy of screening. The authors concluded that increased frequency of screening could potentially improve the detection of stage 1 ovarian cancers hence may lead to improvement in survival. Phase 2 of the trial was designed to investigate 4-monthly surveillance on a sample of 4531 high risk women. Recruitment to this phase has ended with results to be published late 2015.

Primary prevention

Interventions for the primary prevention of breast/ovarian cancer in high risk women comprise chemoprevention, RRM and RRSO.

Chemoprevention

Chemoprevention is defined as “the use of natural, synthetic, or biologic chemical agents to reverse, suppress, or prevent carcinogenic progression to invasive cancer” (Tsao, Kim & Hong, 2004, p. 150). In relation to breast and ovarian cancer, chemoprevention strategies aim to exploit hormone related pathways which influence cancer development. Notably, oestrogen acts as a potent growth factor for breast cancer cells and increased serum concentrations of oestrogen are strongly associated with the development of breast cancer (Travis & Key, 2003). Several drugs are available which decrease exposure to oestrogen: aromatase inhibitors (AIs) which work by blocking oestrogen production and selective oestrogen receptor modulators (SERMs) which block the effects of oestrogen on breast tissue (Calderon-Margalit &

Paltiel, 2004). SERMs have been most widely used and studied and currently form the mainstay of chemoprevention of breast cancer (NICE, 2013). Tamoxifen is the most widely used SERM although several newer agents are under investigation (Howell & Evans, 2013).

There is well established evidence tamoxifen, a non-steroidal anti-oestrogen agent, improves disease-free and overall survival in women with breast cancer (NICE, 2013). Consequently, a number of clinical trials have been designed to assess the efficacy and safety of tamoxifen as a chemoprevention agent. The largest of these was the US Breast Cancer Prevention trial which recruited 13,388 women aged 35 and older between April 1992 and September 1997 (Fisher et al., 1988). The double-blinded trial randomly assigned women to receive tamoxifen 20mg daily (n=6706) or placebo (n=6681) for five years. Early data suggested a benefit in taking tamoxifen over placebo with a reduction in breast cancer development of 45% in the tamoxifen group. This prompted the investigators to unblind the trial and disclose the findings early to allow the women in the placebo group to take tamoxifen in view of its reported clear benefits in lowering breast cancer risk. However, the adverse event profile was greater in the tamoxifen group where there were statistically significant increases in endometrial cancers, cataracts, pulmonary emboli and deep venous thrombosis. The exception was fractures where a protective effect from tamoxifen was found. Fisher et al. (2005) later published seven-year and final update data which reported similar reductions in breast cancer incidence among women taking tamoxifen and comparable rates of adverse events. Additionally, although more breast cancers developed in the placebo group, deaths from breast cancer was not statistically different between the groups therefore an overall positive impact on survival was not equivocally demonstrated (Fisher et al., 2005). Subsequent large, international clinical trials of tamoxifen to reduce breast cancer risk in high risk women have confirmed its potential to significantly lower breast cancer risk but also confirmed the

associated increased risk of adverse events (Cuzick et al., 2002, 2007; Visvanathan et al., 2009).

The unfavourable side effect profile of tamoxifen has led to efforts to source other SERMs which may be beneficial in reducing breast cancer risk (Vogel et al., 2010). The Study of tamoxifen and raloxifene (STAR) trial (Vogel et al., 2006, 2010) was one of the largest and involved almost 20,000 high risk postmenopausal women. Results demonstrated that raloxifene was slightly less effective than tamoxifen in reducing breast cancer risk but conferred a lower risk of endometrial cancer development, thromboembolic events and cataracts than tamoxifen (Vogel et al., 2010).

In summary, tamoxifen and raloxifene are used to lower breast cancer risk in high risk women but confer a number of potential adverse events. Evidence suggests the benefit is greatest in preventing oestrogen receptor positive cancers with little or no effect on oestrogen receptor negative cancers (Cuzick et al., 2013). Since the majority of BRCA1 mutation carriers are more likely to develop oestrogen receptor negative cancers, women with mutations in BRCA1 may not benefit from tamoxifen or raloxifene (Calderon-Margalit & Paltiel, 2004) and further trials are needed to determine the specific effects of chemopreventive agents on different types of BRCA1/2 mutations (Cuzick et al., 2013; Visvanathan et al., 2009).

Risk reducing surgery (RRS)

RRS is the principle primary intervention for reducing breast/ovarian cancer risk (Guillem et al., 2006; Ingham et al., 2013). The aim of RRS is to prevent cancer mortality whilst minimising the potential negative sequelae of such interventions (NICE, 2013).

Risk reducing mastectomy (RRM)

RRM is the surgical removal of the breast in the absence of malignancy to reduce the risk of breast cancer developing (NCI, 2014). No surgical technique is able to remove all breast tissue since it is spread anatomically across the entire anterolateral chest wall and axilla, therefore a balance must be struck between removing maximal amounts of breast tissue and leaving a physically and cosmetically acceptable result (Guillem et al., 2006).

Several mastectomy techniques exist under different names which reflect the degree of tissue removed. Total mastectomy provides greatest breast cancer protection since it involves removal of the entire breast including the nipple and areola complex (NCI, 2014). Subcutaneous mastectomy preserves the nipple and areola complex but leaves the most residual tissue (Guillem et al., 2006) hence a greater risk of cancer development (Zagouri et al., 2013). More recently, the total skin sparing mastectomy (TSSM) has been proposed as an effective method for maximising breast tissue removal and cosmesis (Zagouri et al., 2013). TSSM removes the breast tissue but the entire skin envelope of the breast, including the outer nipple and areola complex, are left intact (Peled et al., 2012). Peled et al. (2012) undertook the largest review to date on TSSM carried out on 657 breasts (428 patients) between 2001 and 2010. The data obtained showed no significant negative oncologic or post-operative outcomes leading the authors to conclude TSSM is both oncologically safe and technically viable, although the relatively short period of follow up of the women was acknowledged. However, skin sparing mastectomy can leave behind as much as 10% residual breast tissue therefore longer term follow up studies are required to confirm its overall oncological safety (Salhab et al., 2010).

Risk reducing salpingo-oophorectomy (RRSO)

Since oestrogen is a potent growth factor in the development of breast cancer, RRSO reduces the risk of both breast and ovarian cancer (Domchek et al., 2010; Guillem et al., 2006). Interestingly, although most BRCA1 associated tumours are oestrogen receptor negative, RRSO still has a protective effect which is believed to occur owing to a reduction in circulating oestrogen metabolites with carcinogenic properties (Salhab et al., 2010). High risk women are therefore recommended to undergo RRSO once childbearing is complete and prior to natural menopause (Challberg et al., 2011). RRSO involves the surgical removal of both ovaries and fallopian tubes since BRCA mutations also confer a higher risk of fallopian tube and peritoneal cancers (Salhab et al., 2010). Similar to RRM, it is not possible to remove all ovarian epithelial tissue and a residual amount of tissue will remain following RRSO (Guillem et al., 2006).

RRSO is generally carried out laparoscopically (Ingham et al., 2013) unless extensive intra-abdominal adhesive disease is suspected (Ward, 2015). Laparoscopic RRSO is argued to be a relatively straightforward from a surgical perspective (Guillem et al., 2006) although as with any surgical procedure, adverse effects are possible. A key issue with RRSO is the surgical induction of early menopause and the potential physical and emotional sequelae of such, which is explored in more detail later on in this chapter.

Impact of RRS on cancer risk and cancer survival

Studies consistently show a reduction in breast cancer risk/development following RRS in high risk populations (Domcheck et al, 2010; Lostumbo et al., 2010; Guillem et al., 2006; NICE 2013). The first study to quantify risk reduction estimates in BRCA1/2 mutation carriers was initiated by Rebbeck et al. (2002) who followed BRCA1/2 mutation carriers recruited from 22 North American and European centres between 1974 and 2008 (follow up was until the end of 2009). Rebbeck et al. (2002) reported

RRSO prior to menopause reduced ovarian cancer risk by approximately 85% and breast cancer risk by approximately 25% in BRCA1/2 mutation carriers. Eight (n=259, 3.1%) ovarian cancers were diagnosed at or following RRSO compared with 58 cancers (n=292, 19.9%) in matched controls with a mean follow up of between five and 8.8 years. Data on breast cancer risk reduction were later reported by Rebbeck et al. (2004) who reported RRM with RRSO reduced breast cancer risk by as much as 95% in BRCA1/2 mutation carriers while RRM alone reduced breast cancer risk by 90% in BRCA1/2 mutation carriers with intact ovaries. Mean follow up was 6.4 years in which two women (n=105, 1.9%) who underwent RRM developed breast cancer compared with 184 (n=378, 48.7%) in matched controls.

Domcheck et al. (2010) reported later findings following the end of the PROSE study follow-up period. Risk reduction estimates were expressed as hazard ratios where possible. BRCA1/2 mutation carriers with no history of breast cancer who underwent RRSO had a lower risk of ovarian cancer compared with those who did not (6% vs 2%; HR, 0.28 [95% CI, 0.12-0.69]) and a lower risk of first diagnosis of breast cancer in BRCA1 mutation carriers (20% vs 14%; HR, 0.63 [95% CI, 0.41-0.96]) and BRCA2 mutation carriers (23% vs 7%; HR, 0.36 [95% CI, 0.16-0.82]). No breast cancers were detected in BRCA1/2 mutation carriers who underwent RRM (n=247) compared with 98 breast cancers (n=1372, 7%) in BRCA1/2 mutation carriers did not. Overall, RRM was confirmed as conferring a statistically significant decreased risk of breast cancer in BRCA1/2 mutation carriers and RRSO as conferring a statistically significant decreased risk of breast and ovarian cancer in BRCA1/2 mutation carriers.

Domcheck et al. (2010) also reported mortality and morbidity data from the PROSE study. A survival benefit for RRM alone could not be demonstrated however in women who underwent RRSO compared with those who did not, there were fewer diagnoses of ovarian cancer (1.1% vs 5.8%) and breast cancer (11.4% vs 19.2%) and

lower all-cause mortality (3.1% vs 9.8%). Recent data reported by Finch et al. (2014) confirms RRSO reduces ovarian cancer risk and all-cause mortality. Following a mean follow up of 5.6 years, RRSO was associated with an 80% reduction in the risk of ovarian, fallopian tube, or peritoneal cancer in BRCA1/2 mutation carriers and a 77% reduction in all-cause mortality.

Ingham et al. (2013) presented survival data from a study involving 345 BRCA1 mutation carriers and 346 BRCA2 mutation carriers with no history of breast or ovarian cancer which demonstrated an overall survival benefit with any type of RRS (RRM and/or RRSO) which are summarised in Table 2 below. Although all-cause deaths were recorded, the authors reported the majority of deaths occurred from breast or ovarian cancer. Ovarian cancer deaths were more common than breast cancer deaths in BRCA1 carriers. Additionally, it was reported a reduction in mortality was found in women undergoing RRM alone but this was not statistically significant once adjusted for age.

Table 2: Survival rates according to risk reducing intervention (Ingham et al., 2013)

Procedure/number of women	Number of deaths	10 year survival
No RRS/n=457	71	84.3% (95% CI, 80.1 – 87.8%)
RRM/n=58	1	98.1% (95% CI, 87.1 – 99.7%)
RRSO/n=108	4	98.2% (95% CI, 92.9 – 99.6%)
RRM and RRSO/n=68	1	98.3% (95% CI, 88.6 – 99.8%)

To sum up, there is convincing evidence RRS lowers the risk of breast/ovarian cancer in high risk women, but estimates of the magnitude of reduction vary. Furthermore, RRS does not entirely negate risk (Lostumbo et al., 2010). The remaining risk of breast cancer post RRM is believed to be 10% or less with an approximately 5% risk for peritoneal carcinoma post RRSO (Lodder et al., 2002) although these

figures have yet to be adequately quantified. Evidence regarding the impact of RRS on survival is weak (Neuburger et al., 2013) and further studies are needed to compare RRS with optimal screening (Domchek et al., 2010). If a high risk woman elects not to undergo RRS and has effective surveillance and intervention should breast cancer develop, the paradox is that she may be cured by less extensive breast conservation surgery (Lostumbo et al., 2010; Press, Fishman & Koenig, 2000).

Impact of RRS

The surgical removal of any body part exposes people to anaesthetic and surgical risks (Bosma, Veen, de Jongh & Roukema, 2012) and the invasive effects of surgery may impact negatively on body image (Atkinson & Pudner, 2010). General risks of surgery and anaesthesia include pain, infection, septicaemia, haematoma formation, haemorrhage, major organ dysfunction, thrombosis formation, nerve damage, skin breakdown and death (Bosma et al., 2012). Women who undergo RRM with breast reconstruction additional face risks associated with these procedures and younger women undergoing RRSO must also contend with issues surrounding premature, surgically induced menopause. Not surprisingly then, both RRM and RRSO have the potential to cause physical and psychological morbidity (Altschuler et al., 2008).

Evidence suggests women undergoing RRS experience a range of adverse events and a degree incapacitation for which they are largely unprepared (Hatcher & Fallowfield, 2003; Rolnick et al., 2007). The most commonly reported physical symptoms post-RRM include numbness and loss of sensation (Barton et al., 2005; Gahm, Wickman & Brandberg, 2010; Hallowell et al., 2012; Metcalfe, Esplen, Goel & Narod, 2004; Rolnick et al., 2007), tingling sensation (Gahm et al., 2010; Metcalfe et al., 2004), pain (Barton et al., 2005; Bresser, 2009; Gahm et al., 2010; Hallowell et al., 2012; Rolnick et al., 2007) and infection (Barton et al., 2005; Gahm et al., 2010; Metcalfe et al., 2004). Other reported adverse events include swelling (Metcalfe et al.,

2004), seroma formation/lymphatic fluid leakage (Barton et al., 2005), limited arm movement (Barton et al., 2005; Hatcher & Fallowfield, 2003) and difficulty sleeping (Gahm et al., 2010; Hatcher & Fallowfield, 2003).

Post-operative complications frequently necessitate additional surgical interventions cumulatively exposing women to further surgical risks (Barton et al., 2005), more so if breast reconstruction is also carried out (Gopie et al., 2013; Guillem et al., 2006; Rebbeck et al., 2004). Zion et al. (2003) reported 6% of women undergoing RRM without reconstruction (n=318) required at least one further operation compared to 52% of women who had also undergone reconstruction (n=1099), mostly related to implant problems. Hatcher and Fallowfield (2003) likewise found implant removal because of infection to be problematic following RRM with half of respondents reporting post-operative complications still ongoing 18 months after surgery. More recently, Koskenvuo, Svarvar, Suominen, Aittomäki and Jahkola (2013) reported findings on 55 women undergoing either bilateral or contralateral RRM, 85% of who also underwent breast reconstruction with autologous tissue transfer and/or implant insertion. Overall, 42% of women experienced complications which required re-operation. Almost a third of complications were due to problems with autologous tissue transfer and 42% were a result of implant problems.

The physical impacts of breast removing surgery have emotional consequences which may lead to women having negative feelings towards their post-surgery bodies as a result of scarring, changes and altered body image (Brandberg et al., 2008; Hallowell et al., 2012; Lindwall & Bergbom, 2009). A relationship also exists between increasing incidence and severity of surgical complications and reduced psychological wellbeing (Hopwood et al., 2000) and regret following surgery (Gahm et al., 2010), highlighting again how RRS has the potential to significantly impact on physical and emotional wellbeing.

RRSO also involves a range of potential adverse physical impacts as a result of the surgical procedure itself and the resulting loss of ovarian function in premenopausal women. In addition to the general risks of surgery, RRSO can result in excessive bleeding (Kauff et al., 2002; Meeuwissen et al., 2005), urinary and bowel problems (Guillem et al., 2006; Kauff et al., 2002; Michelsen, Dørum & Dahl, 2009) and pain/discomfort (Fang, McKenzie, Miller and Daly, 2005; Madalinska et al., 2005; Michelsen et al., 2009).

Moreover, in premenopausal women, a surgical menopause is induced resulting in an abrupt decline in gonadal hormones (Kotz, Alexander & Dennerstein, 2006). The resulting oestrogen deprivation is associated with an increase in severity of menopausal symptoms and negative bodily changes which impact on physical and emotional well-being, more so than the more gradual decline which accompanies natural menopause (Bresser, 2009). Loss of ovarian function following RRSO results in a range of negative sequelae including vaginal dryness (Bonadies et al., 2011; Fang et al., 2009; Finch et al., 2011; Robson et al., 2003), night sweats and hot flashes (Bonadies et al., 2011; Finch et al., 2011; Tollin, 2011), sleep disturbances (Bonadies et al., 2011; Tollin, 2011), hair thinning (Bonadies et al., 2011) cognitive changes (Guillem et al., 2006), dyspareunia (Bonadies et al., 2011; Fang et al., 2009; Finch et al., 2011; Hallowell et al., 2012), weight gain and change in body shape (Bonadies et al., 2011; Hallowell et al., 2012).

Oestrogen deprivation is also associated with higher risks of all-cause mortality (Sharma, 2011), a loss of bone mineral density resulting in an increased risk of osteoporosis and bone fracture (Cohen et al., 2012; Guillem et al., 2006; Sharma, 2011) and an increase in onset and incidence of cardiovascular disease (Guillem et al., 2006; Sharma, 2011) which may shorten lifespan (Howell & Evans, 2011). The increasingly recognised health risks associated with premature menopause

(Domcheck et al., 2010) requires a judgement to be made regarding the use of hormone replacement therapy (HRT) in high risk women who undergo RRSO (Finch et al., 2014). HRT reduces menopausal symptoms and is associated with benefits to cardiovascular and bone health (Bresser, 2009; Rebbeck et al., 2009) but also confers an increase in breast cancer risk in the general population (Beral, Reeves, Bull & Green, 2011; Fournier, Berrino, Riboli, Avenel & Clavel-Chapelon, 2005) although studies exploring this link are of varying quality (NICE, 2013). The increased risk observed in the general population raises legitimate concerns that HRT use may negate the protective effects of RRSO in BRCA1/2 mutation carriers (Rebbeck et al., 2005). Several studies have reported observational data which suggests HRT does not increase breast cancer risk in women undergoing RRSO (Anderson et al., 2003; Challberg et al., 2011; Rebbeck et al., 2005). Furthermore and somewhat paradoxically, Rebbeck et al. (2009) reported RRSO in women under 45 years of age may be associated with increased mortality if HRT is not taken due to the risks to cardiovascular health. Further research is needed to determine the benefits and risks of HRT use in BRCA1/2 carriers (Domcheck et al., 2010; Madalinska et al., 2006; Rebbeck et al., 2009).

In addition to the physical risks outlined above, the folklore and symbolisation attached to female breasts and ovaries in Western society means RRS exposes women to potential negative psychosocial impacts (Schulzke, 2011). Breast loss is more often constructed as an emotional rather than physical crisis because it is equated with a loss of sexual identity and attractiveness (Rubin & Tanenbaum, 2011) and ovarian loss is associated with a negative effect on body image, femininity and personal identity (Hallowell et al., 2012). Commonly reported psychosocial impacts of RRS include a negative impact on body image (Altschuler et al., 2008; Bonadies et al., 2011; den Heijer et al., 2012; Gopie et al., 2013; Hallowell et al., 2012; Kurian et al., 2005; Sheppard & Ely, 2008) sexuality (Altschuler et al., 2008; Kurian et al., 2005;

Rubin & Tanenbaum, 2011; Sheppard & Ely, 2008) and sexual activity or functioning (Bonadies et al., 2011; Gahm et al., 2010; Hallowell et al., 2012; Sheppard & Ely, 2008). Women also report feeling less attractive following RRS (Gahm et al., 2010; Gopie et al., 2013; Rubin & Tanenbaum, 2011; Sheppard & Ely, 2008) and experience reduced emotional wellbeing associated with cosmesis, 'womanliness' and the irreversibility of the surgery (Altschuler et al., 2008; Howard, Balneaves, Bottorff & Rodney, 2011; Sheppard & Ely, 2008).

Negative psychosocial impacts can present as a result of the surgery itself but may also be exacerbated by physical impacts such as pain, swelling, loss of sensation (Gahm et al., 2010; Gopie et al., 2013) and oestrogen deprivation (Bonadies et al., 2011). The post-operative period can also incur a period of immobilisation which results in absence from work and interferes with home and family commitments (Hallowell, 1998) which may be longer than anticipated if complications and further operations are required (Gopie et al., 2013).

Overall then, RRS is associated with a number of potential negative impacts on physical and psychosocial wellbeing, but at the same time, the procedure does reduce risk in high risk populations therefore offers a degree of protection from cancer and its harmful effects. The potential to reduce cancer-related worry/anxiety was largely presented in the literature as the most positive impact of RRS (Hatcher & Fallowfield, 2003; Fang et al., 2005; Gopie et al., 2013; Guillem et al., 2006; Hallowell et al., 2012; Hatcher, Fallowfield & A'Hern, 2001; Hopwood et al., 2000; Litton et al., 2009; Lodder et al., 2002; Lostumbo et al., 2010; van Dijk et al., 2003). Such findings have led to suggestions that RRS may be the only way high risk women can effectively reduce cancer worry (Litton et al., 2009). However, the relationship between reducing cancer worry and RRS is not straightforward. Although an anticipated reduction in cancer worry is a key driver in the decision to undertake RRS (Fry, Rush, Busby-Earle

& Cull, 2001a; Hatcher & Fallowfield, 2003; Lodder et al., 2002; Litton et al., 2009) women with high levels of cancer worry who undertake RRS report equivalent levels of cancer worry following surgery to women who do not have RRS (Fry, Busby-Earle, Rush, & Cull, 2001b). Furthermore, cancer-related worry was also found to be linked to the impact of surgery in terms of satisfaction and regret following surgery. Women who exhibited greater cancer-worry and anxiety were less likely to be satisfied with the results of surgery (Metcalf et al., 2004) and felt most regret following surgery (Fuller & Anderson, 2006). This is concerning as it suggests women may be driven by worry to undertake RRS yet may remain worried and experience less satisfaction and more regret following surgery.

To conclude this section, RRS is an effective way of controlling cancer risk in high risk populations but much remains unknown about the best way to manage women at high risk of HBOC (Kurian et al., 2010; NICE, 2013). Although RRS may reduce cancer-specific distress, this is replaced by other problems including negative impacts on physical, emotional and psychosocial health (Gopie et al., 2013). Decision-making about RRS can thus be understood as a negotiation of competing risks to body and self: although surgery may offer protection from cancer, the folklore in Western society surrounding the female breasts, and to a lesser extent the ovaries, means surgery to remove these organs results in other risks to a woman's body and self-identity (Howard et al., 2011).

Surgical interventions on women's bodies in response to risk can be understood as an expansion of medicalisation whereby risk is treated in the same way as disease (Conrad, 2007). The next section explores this concept further through a critique of medicalisation, risk and risk management practices in relation to HBOC.

Medicalisation, risk and HBOC

The concepts of medicalisation and risk were useful in this study as a means of positioning HBOC within wider societal and medical discourses which impact on high risk women and their experiences. The discussion to follow therefore provides a background against which women's decisions to refuse RRS are contextualised. The examination of risk as a medicalised phenomenon in Western society adds to contemporary understandings of how cancer risk is constructed and managed. Furthermore, the ongoing and increasing medicalisation of women's breasts and ovaries in Western society is understood as a product of emerging genetic and medical technologies which both define and produce women's bodies in particular ways and allow still-healthy organs to be surgically removed on the basis of risk. Attention is also drawn to the medicalisation of the female breast, as exemplified through the normalisation of cosmetic and reconstructive breast surgery, which serves as evidence of the importance placed on women's breasts in Western society, a key area of concern in this study.

Medicalisation

The concept of medicalisation is used to examine ways in which aspects of human life are constructed as medical problems requiring intervention (Maturo, 2012). Although the disease of breast/ovarian cancer is real, the women in this study were disease-free yet they faced surgical 'treatment' to prevent a potential future cancer from occurring. This represents a medicalisation of risk (Maturo, 2012) as risk factors themselves are perceived as disease (Conrad, 2005, 2007).

Riska (2003) claimed the trend in biomedicine to focus on how individuals' behaviours influence disease development, promotes a risk-factor approach to health. Breast cancer risk in particular is frequently associated with so-called 'lifestyle factors' (Finkler, 2000), fuelling a wide body of research aimed at modifying women's lifestyles

in order to reduce cancer risk (Chlebowski, 2010). Thus, an individual's lifestyle and habits are constructed as risk factors for certain diseases which can be modified through compliance with medicine. Such assumptions about health and disease further drive medicalisation in Western society because individuals charged with self-responsibility for health seek increasingly technical medical solutions to repair their 'broken' bodies (Conrad, 2005).

Of particular relevance to this study, it has been argued in this era of genomic medicine (Conrad, 2005), that the hegemony of the gene (Finkler, 2000) has placed genetics at the centre of the public and professional dialogue on cancer (Maturo, 2012). Modern medicine's seemingly increasing ability to identify individuals at risk of disease by nature of their genetic make-up problematises the concept of health itself. Genetics further drives medicalisation by expanding the medical gaze to include people with no pathology but who may develop disease at a point in the future (Crabb, 2006; Riska, 2003) because perceptions of the value of genetic tests are vastly inflated (Conrad, 2005; Finkler, 2000; Lock & Nguyen, 2010; Melzer & Zimmerman, 2002).

Moreover, the availability of genetic information on people regarding their future risk of disease has created a new category of 'patient': those who are pre-disease (Webster, 2002). Genetic testing allows the identification of people who are "potentially ill" (Conrad, 2005, p. 8), "genetically at risk" (Novas & Rose, 2000, p. 486) or what Finkler (2000, p. 58) referred to as "perpetual patients without symptoms". Timmermans and Buchbinder (2010, p. 409) similarly argued genetics had led to a population of people trapped between normalcy and pathology as "patients-in-waiting". Genetic testing thus has the potential to do more harm than good by marking people for disease which may never happen or cause a threat to health (Faulkner, 2012).

Medicalisation and female experience

The concept of medicalisation is particularly useful in examining women's health experiences owing to the patriarchal nature of Western medicine which tends to support traditional male/female roles in society (Kennedy & Kennedy, 2010; Waitzkin, 1978, 1989) and categorise medical issues on the basis of gender (Bilton, et al., 2002; Griffiths et al., 2010). Consequently, normal female experiences such as childbirth, menstruation and menopause have been medicalised in Western society (Purdy, 2001; Riessman, 1983; Westfall & Benoit, 2008; Wylie, Potter & Bauchspies, 2012). The menopause for example, is viewed as a hormonal deficiency which predisposes women to heart disease, osteoporosis, Alzheimer's disease and ultimately a premature death. Other factors such as diet, exercise and socio-economic factors which have a greater impact on female longevity receive less attention (Riska, 2003). The medicalisation of women's experience is arguably no more evident than in relation to the breasts. In this study, it is argued women and their bodies and breasts are medicalised as a result of social and cultural assumptions about women's bodies which allow elective surgical interventions on healthy breasts, for 'cosmetic' reasons or for cancer risk.

Women's breasts have been manipulated by societal discourses and the medical profession for some time. The first surgical correction of the breasts is believed to have taken place in 17th century Europe when a woman's very large breasts were surgically removed by a barber to reduce the pain and embarrassment caused (Ferguson, 2000). Until the 20th century, surgery to the breasts was primarily carried out to remove tumours or reduce the size of large breasts (Jacobson, 1998). Interventions to enlarge breasts are a relatively modern phenomenon, reflecting changing social and cultural expectations of what women should look like (Darling-Wolf, 1997) and how cosmetic surgery is tailored to meet the body aesthetic considered 'fashionable' in different times and cultures (Riggs, 2012).

Coco (1994) identified culturally specific perceptions of the female breast drove medicalisation and created the “official breast” (Coco, 1994, p. 35). The official breast conformed to externally-imposed cultural norms and values against which other breasts were viewed as substandard and deviant. The medicalisation of women’s breasts was palpably exposed in the 1980s when the American Society of Plastic and Reconstructive surgeons (ASPRS) used the term ‘micromastia’ to describe the ‘disease’ of small breasts (Wilson, 2002). Micromastia medicalised and pathologised small breasts, identifying them as something abnormal that required an operative cure (Ferguson, 2000). The following quote from a past president of the ASPRS, taken from Coco (1994, p. 32) accentuates the derision with which small breasts were viewed and the perceived link between a woman’s breasts and life experience:

(...) these deformities [small breasts] are really a disease which result in the patient’s feelings of inadequacy, lack of self-confidence, distortion of body image and a total lack of well-being due to lack of perceived femininity. The enlargement of the underdeveloped breast is therefore very necessary to ensure the quality of life of the patient.

Consequently, a double pathology is evident (Ferguson, 2000): small breasts constitute a disease and the trauma caused by having small breasts causes psychological distress in need of medical treatment. Medicalisation thus allows medical practice to act as a vehicle for controlling breasts which are considered deviant for the purpose of securing conformity with social norms (Thomas-Pollei, 2008).

Breast augmentation surgery is now the most common cosmetic procedure globally and rates have increased by more than 800% since the 1990s (Lavigne et al., 2013). Most breast augmentations are carried out in women aged 20 – 30 years (Wilson, 2002) although in Brazil, age 15 is considered the ideal age for enlarging breasts (Riggs, 2012). Since implants last on average 10 – 15 years, most women will require multiple surgical interventions to maintain their altered breasts. Breast

enlargement has been carried out using injections of paraffin and wax and insertion of glass balls, plastic wool, animal fat, ivory, ox cartilage and synthetic sponges (Donohoe, 2006). The first documented use of silicone to enlarge breasts dates back to the Second World War, when silicone in the form of engine coolant, was injected into the breasts of Japanese prostitutes to suit the preferences of American servicemen (Ferguson, 2000). Silicone injections directly into the breast were considered too dangerous by the American Food and Drug Agency hence silicone implants were developed as a safer alternative (Darling-Wolf, 1997).

Since the 1950s, silicone gel filled implants have been the intervention of choice to enlarge women's breasts (Donohoe, 2006). In the booming cosmetic surgery market, the previous medical use of silicone in devices including urinary catheters, intravenous tubing and pacemakers ostensibly made it the ideal synthetic for enlarging breasts. However, silicone is not as inert as previously believed and silicone entering the bloodstream has been linked to reports of blindness, gangrene, auto-immune disorders (Ferguson, 2000) and connective tissue diseases and neurological disorders (Donohoe, 2006). Other complications associated with silicone breast implants include decreased sensitivity of the breasts and nipples, painful swelling and hardening of the breasts, implant rupture and encapsulation (Wilson, 2002). Between 1985 and 1998, around 180,000 adverse reactions and 118 deaths have allegedly occurred as a result of silicone implant insertions (Ferguson, 2000). Post-augmentation surgery complications are associated with an increase in depression and suicide, especially in relation to multiple implant surgeries (Breiting et al., 2004). Breast augmentation decreases the sensitivity of mammography (Donohoe, 2006) and although no evidence has been found to suggest silicone implants cause breast cancer, the presence of silicone implants may delay diagnosis of breast cancer and adversely affect survival following diagnosis (Lavigne et al., 2013).

In contemporary Western society, female breasts are medicalised to the extent plastic surgeons are now able to define and construct the 'perfect breast' (American Society of Plastic Surgeons (ASPS), 2014). The concept of the 'perfect' breast derived from the writings of plastic surgeons Mallucci and Branford (2012, 2014) who aimed to produce a guide for women and surgeons to achieve "more acceptable, longer lasting results and ultimately more beautiful breasts" (ASPS, 2014, para 12). Mallucci and Branford (2012) undertook an observational study of the breasts of 100 topless models identified by the editors of a tabloid newspaper as having the most attractive breasts and compared these with women identified as having 'less attractive breasts' in order to define "critical ideals of breast beauty" (p. 65). A follow-up survey (Mallucci & Branford, 2014) was conducted to determine the ideal breast and concluded the "upper pole to lower pole ratio of 45:55" had universal appeal in defining the perfect breast hence "this proportion should be used as a basis for design in aesthetic surgery" (Mallucci & Branford, 2014, p. 436) as deviation from the 'norm' produced less attractive breasts. Such suggestions reify the 'perfect breast' as something women need and completely preclude discussion of social, cultural and economic drivers in breast medicalisation and the potential harmful effects of a medically unnecessary surgical procedure.

Equally it can be argued the prominence of surgical breast reconstruction in definitions of breast cancer treatment (Haines et al., 2010) further medicalises the breasts and promotes a view women without breasts are deviant and/or diseased (Crompvoets, 2012; Ferguson, 2000). Cobb and Starr (2012) drew parallels between breast reconstruction post-mastectomy and cosmetic breast surgery and argued both are aesthetic practices which promote a view women need a particular body and breast type. This serves as evidence of medicalisation of the female breasts/body because both are socially mandated but medically unnecessary procedures. Furthermore, the prominence of cosmetic surgery has been argued to drive

expectations women's breasts can be improved following RRS and reconstruction (de la Peña-Salcedo, Soto-Miranda & Lopez-Salguero, 2012). In the de la Peña-Salcedo et al. (2012) paper, examples of such improvements are provided, namely large, spherical, silicone implants which are significantly greater in size than the woman's pre-operative breasts, accompanied by the commentary "Note the postoperative aesthetic outcome, by far better than the preoperative condition" (p. 144). There is, as Löwy (2010, p. 215) claimed, a promise of "new breasts for the old" which supports the medicalisation of women's breasts and bodies and promotes a particular type of breast as acceptable and necessary.

However it must also be acknowledged the relationship between medicalisation and the body/breasts is complex and multi-factorial because medical interventions have unquestionably improved many areas of women's health. Purdy (2001) rightly points out some areas of health which have been medicalised such as infertility and childbirth are at least in part medical issues. Thus medicalisation is not fundamentally unwelcome but rather part of the problem and the solution to improving women's health (Riessman, 1983). Although childbirth has been largely medicalised in Western society, accompanying improvements in pain relief, infection and mortality have resulted (Riessman, 1983). Breast augmentation surgery can give women a feeling of being empowered by doing something positive about looks in order to resemble the norm (Cheek & Porter, 1997) hence a medical diagnosis can support a woman's legitimate claim for breast enlargement surgery for mental health reasons (Conrad, 2005). Moreover, cosmetic breast surgery may serve as a means of achieving social and economic security for some women whose life circumstances are otherwise curtailed (Davis, 1995; Morgan, 1991). Breast reconstruction following breast loss may impact positively on quality of life and improve body image (Bresser, 2009). Furthermore, once a disease or condition is medically authenticated and endorsed, social stigma is reduced and shortcomings in the individual which may have been

attributed to the development of the condition are mitigated, hence medicalisation may offer comfort to those afflicted (Lock & Nguyen, 2010). Thus women are not merely passive victims of medicalisation, but may seek medical intervention in order to improve their lives and life experiences (Conrad 2007; Green, Thompson & Griffiths, 2002; Griffiths et al., 2010; Lock & Nguyen, 2010).

In summary, the concept of medicalisation applied to this study suggests the risk of breast/ovarian cancer is now conflated with the disease of breast/ovarian cancer, allowing medical interventions to remove healthy breasts and ovaries. Furthermore, the normalisation of cosmetic surgery and the essentialness of reconstruction following mastectomy medicalises women's breasts and bodies and stigmatises women with breasts which are absent or 'deviant'. This is the reality faced by the women in this study: the medicalisation of risk means RRS appears *prima facie* to be the obvious action to deal with cancer risk. What is concealed in the medicalisation discourse is the uncertainty associated with genetic risk calculation for individuals and ways in which perceptions of risk influence decision making in response to risk. The next section further explores the concept of risk and examines how differing constructions and perceptions of risk may influence how people and institutions such as medicine respond to risk.

The concept of risk

This study concerns women identified as high risk of developing breast and/or ovarian cancer who say no to RRS despite evidence of its effectiveness in lowering cancer risk, a decision which is argued to be at odds with Western medical discourse on how best to attend to risk. Accordingly, a review of the concept of risk is mandatory as perceptions of risk and decision making in response to risk are key concepts in providing a framework for understanding the women's stories in relation to their high risk status and RRS.

Health care is increasingly organised, described and practised around the construct of risk (Maturo, 2012; Robertson, 2000). Within medical discourse, risk is now established as a fundamental feature of cancer development (Davis, 2008) and as a key construct in public health and preventative medicine (Hallowell & Lawton, 2002). The concept of risk has been extensively written about and problematised across the social and natural sciences. Across disciplines, risk is generally agreed to be about uncertainty and response to uncertainty. However, the conceptualisation of risk differs according to discipline-specific assumptions about the nature of the human world. Irrespective of the stance taken, a politics of risk now exists and public and professional debate is intensified through scientific, medical and legal discourses on the nature of risk and how risk impacts on people's everyday lives (Tulloch & Lupton, 2003).

Risk in the natural sciences

In the natural sciences including medicine, the concept of risk is grounded in assumptions about the natural world and the laws of nature which govern it. Risk is defined as the probability distribution of harmful events and risk calculation uses statistical computations based on binary logic utilising probability theory (Grossi, 2005). This traditional approach to risk values logic and positions humans as rational actors who make sensible decisions based on objective truths when faced with risk (Taylor-Gooby & Zinn, 2006).

From a medical perspective, the concept of risk is most frequently associated with factors which modulate the probability of a disease or condition occurring, worsening or improving. There is a focus on identifiable, measurable risk factors, causal relationships and statistical models which predict outcomes (Costa & Carneiro, 2011; Offord & Kraemer, 2000) so that risk can be reduced and future harm prevented through accepted health promotion strategies (Costa & Carneiro, 2011; Ilkilic, 2009).

In medicine, information from clinical and epidemiological studies is used to collate evidence for determining risk. In order to determine cause-effect relationships, randomised controlled clinical trials are considered the 'gold standard' approach (Pearson, 2010). Where this is not feasible, observational case-control and cohort studies are used. These studies typically make comparisons between groups of people with/exposed to the risk factor and groups not carrying/exposed factor in order to calculate an odds ratio of how likely/unlikely an outcome is to occur in different sub groups (Ho, Peterson & Masoudi, 2008). Such studies cannot determine causality, only association between variables and/or risk factors/exposure (Costa & Carneiro, 2011). Epidemiological data identifies risk factors for disease/conditions which are then manipulated through clinical trials. If an overall reduction in harm is demonstrated, the intervention becomes standard treatment for that particular group of patients (Karlavish, 2010).

Risk calculations are used in HBOC management in several ways: to calculate the probability of identifying a deleterious mutation in an individual, to calculate the probability of an individual developing cancer should a mutation be present and to calculate the risks/benefits of risk reducing interventions (Costa & Carneiro, 2011). A number of risk-assessment models have been developed to facilitate risk calculation although no model exists which is able to account for all factors which affect risk (Evans & Howell, 2007). Some of the challenges inherent in calculating risk for breast/ovarian cancer predisposition were discussed earlier in this chapter. In addition, these models are highly complex and arguably beyond the understanding of most people (Klitzman, 2010). To contextualise this, an example of a risk estimation model is shown below.

To construct CIs for the log (RR) estimates, we assumed that the parameters were asymptotically normally distributed with the covariance matrix given by inverting the information matrix. Cumulative risk or penetrance and 95% CIs were calculated from the cumulative incidence $\Lambda(t)$, where $\Lambda(t) = \sum_{k=1}^n i_k t_k \exp(\beta_k)$, where i_k is the incidence in noncarriers in the k th age band of length t_k and β_k is the $\ln(\text{RR})$ in the k th age band. The variance of the cumulative risk is given by the expression

$$\begin{aligned} \text{var}[\Lambda(t)] = & \sum_{k=1}^n i_k^2 t_k^2 \text{var}(\beta_k) \exp(2\beta_k) \\ & + 2 \sum_{j < k, k=1}^n i_k i_j t_k t_j [\text{var}(\beta_k) \text{var}(\beta_j)]^{1/2} \exp(\beta_k) \exp(\beta_j) \text{corr}(\beta_k, \beta_j), \end{aligned}$$

and the cumulative risk $F(t)$ is then given by $F(t) = 1 - \exp[-\Lambda(t)]$, with a 95% CI of $1 - \exp[-\Lambda(t) \pm 1.96 \sqrt{\text{var}[\Lambda(t)]}]$. Uncertainty in RRs for factors with more than two categories (e.g., center) is presented as floating CIs.

Figure 4: Example of a risk estimation equation (taken from Antoniou et al., 2003, p. 1121).

Despite the primacy of risk-estimation models the context of supporting decision making around RRS, some challenges are evident. Studies examining breast/ovarian cancer risk and RRS tend to be observational and use case-control studies or mathematical computations (Lostumbo et al., 2010) owing to ethical challenges in devising a randomised controlled trial to determine causality (Kurian et al., 2010). Indeed as Frasier, Greenberg & Neuman (2015) note, there is no Level 1 evidence which demonstrates a survival benefit with RRS and this is unlikely to ever be available given the ethics associated with randomising women to surgery or no surgery. This means data from studies show an association between RRS and reduced cancer incidence, but cannot categorically determine that surgery caused the reduction in risk. Although risk-estimation models are able to provide information on population risks for breast/ovarian cancer (NICE, 2013) it is not possible to predict which women will go on to develop the disease (Evans & Howell, 2007). If a woman

undergoes RRM and RRSO and does not develop cancer, it is not possible to know if surgery prevented cancer or if she would never have developed the disease in the first place. Furthermore, no risk-estimation model is able to account for all factors which affect risk (Evans & Howell, 2007) and the relationship between genes and the social and physical environment hence individual risk estimates are highly questionable in many circumstances (Lock, 2005). Genetic knowledge in particular is not fixed or absolute and is often anomalous and ambiguous (Timmermans & Buchbinder, 2012), therefore risk calculations require clinicians to use judgement to determine significance of test results and apply to individual people, a judgement which is based on both known and unknown factors.

In summary, risk has become an increasingly important concept in modern medicine. Models of risk calculation are algorithmic, focussing on objective measurements, risk factors and evidence-based risk reducing interventions. The construction of risk as a statistical measure is problematic because it may not be representative of individual risk (Costa & Carneiro, 2011). Furthermore, risk in the medical discourse fails to incorporate individual perceptions and understandings of risk (Timmermans & Buchbinder, 2012) which influence health behaviours (Davis, 2008). In contrast to risk in the natural sciences, sociological perspectives of risk are based on the assumption that all social action, including risk practices, are shaped by social institutions and culture rather than rational planning and logic (Taylor-Gooby & Zin, 2006). The next section therefore focusses on sociological theories of risk which examine perceptions of risk and risk management in social and cultural contexts in order to elucidate how people understand and respond to risk in contemporary society.

Sociological and cultural perspectives on risk

A substantial and growing body of literature on risk exists in the social sciences which reflect the importance of risk as a defining cultural characteristic of modern society

(Maturo, 2012). The increasing complexities of technology and of social institutions which govern people's lives serve not only to identify risk, but also to publicise risk and the at times catastrophic results of technological and social breakdown (Peterson & Wilkinson, 2008). Paradoxically, the increased ability to identify risk has raised awareness of society's inability to control risk and hazards to life. The recognition society and technology are not able to rescue humans from risk politicises risk and gives rise to debate and conflict which has fuelled increasing interest in risk research (Taylor-Gooby & Zinn, 2006). Three key sociological theories on risk are evident in the literature (Brown, 2014; Zinn, 2008): Beck's Risk Society, Douglas' Cultural Theory and Governmentality theory which draws on Foucault's work on modern society and ways in which institutions and organisations exert control over individuals. The discussion to follow focusses on key concepts in relation to the sociology of risk which were particularly relevant to this study.

The Risk Society

One of the first sociological theories of risk was proposed by the German sociologist Ulrich Beck. Beck (1992, p. 21) defined risk as "a systematic way of dealing with hazards and insecurities induced and introduced by modernisation itself". The consequences of modernisation were argued to be a set of risks or hazards which were unlike any previously experienced in pre-modern societies, thus creating a risk society. Beck (1992) argued people's perception and experience of hazards and risk changed as society modernised and related this to a three stage periodisation of social change: pre-modernity, simple modernity and reflexive modernity. In pre-modern societies there was no real notion of the concept of risk (Giddens, 1998). Although hazards and risks to life existed, they were attributed to non-human sources (Taylor-Gooby & Zinn, 2006) and occurred through fate, divine intervention or nature: that is, danger was placed on mankind from 'outside' society (Beck, 1992). As society modernised, the economy and way of life changed and became shaped by

industrial/technological processes and problems. Industrialised societies produced 'goods' such as wealth, employment and technological and scientific advancement but also 'bads' or dangers (Lash & Wynne, 1992) such as pollution, crime and traffic accidents (Zinn, 2008). Modern was not inherently good but rather was increasingly problematic and modern societies were progressively uncertain societies to live in. Beck (1992) referred to this as a process of reflexive modernisation: the modernisation of modern society itself. Reflexive modernisation challenged established ways of knowing and existing social structures because of awareness that societies' dangers and hazards are in the main, created by society itself (Zinn, 2008). A preoccupation with danger and the need to avoid danger through controlling measures gave rise to the concept of risk (Giddens, 1998). Reflexive modernity is thus co-existent with the risk society; in effect its own self-creation resulting from a dystopian industrialised society (Lash & Wynne, 1992). Hence, modern societies are risk societies and being 'at risk' is now an integral part of the human condition (Beck, 2006).

It is important to identify the risk society is no more 'risky' than previous societies (Giddens, 1998). Rather the nature of risk and how risk is perceived and experienced has changed with modernisation (Lupton, 2006; Zinn, 2008). Technological advancement allowed hazards to be identified before they occurred and humans moved from living life as fate to living life as uncertain. Contemporary risks such as radiation and food toxins are often invisible until made visible and defined by experts (Beck, 2006). Likewise, modern technology has allowed genetic mutations to be identified and a category of risk attached. Adam and van Loon (2000) contend this is an area of public concern and suggest genetic technology has superseded nuclear power as the greatest concern in late-modern society.

The technology to define, categorise and measure genetic risk allows experts and expert knowledge to dramatise or minimise risk (Beck, 1992). Breast/ovarian cancer risk is defined by experts then placed onto women as a result of their genetic material, individualising risk (Tulloch & Lupton, 2003) and attaching human responsibility to risk (Lupton, 2006). Risk has come to mean the anticipation of a future bad event, experienced in the present, creating a politics of fear and a politics of prevention (Beck, 2009). Women at high risk of developing cancer are thus expected to manage risk through medical interventions such as RRS, surveillance and chemoprevention, each of which carries its own set of risks. Paradoxically, freedom of choice, autonomy and self-agency are promoted in a society of increasing uncertainty, creating tension between freewill and doing what appears sensible to reduce risk (Zinn, 2008).

Beck's (1992) risk society has been criticised for failing to account for the role inequalities play in modern society and how gender, race and socio-economic influences impact on risk and risk perception (Tulloch & Lupton, 2003). Some have also argued risk society dogmatically over-emphasises the prominence and relevance of risk in everyday life and fails to capture what is essentially different in modern society (Elliot, 2002). Nonetheless, Beck's (1992) risk society is useful in problematising medical and genetics discourses in relation to risk by highlighting how genetic technology has created and heightened awareness of new genetic risks, and placed responsibility for risk at the door of affected individuals, such as the women in this study.

Cultural theory and risk

Another central theory in sociological risk research is the Cultural Theory of risk which draws on the work of anthropologist Mary Douglas and is based on the belief risk practises are a product of acculturation and social learning (Lupton, 2006). Cultural theory forms part of Douglas's (1970) wider typology of Grid and Group societies. In

Douglas's (1970) theory, 'grid' refers to laws, social relations, expectations and other constraints imposed on a group which regulate the actions of individuals. 'Group' refers to how bonded and well-connected group members feel with each other as a result of group dynamics. Different grid/group environments reflect varying degrees of social stratification and social solidarity and therefore how individuals function and participate within groups (Fox, 2000).

In terms of risk, cultural theory supports a social constructionist view of risk and contends different risk responses are entwined with different patterns of social organisation and how people perceive risks to their group/society (Brown, 2014; Fox, 2000). Like Beck (1992), Douglas (1992) claimed the meaning associated with risk changed over time. Historically, risk was a neutral concept as it took account of the probability of both losses and gains which could result from an action or event. However as society modernised, Douglas (1992) argued risk became equated only with loss. Whereas previously 'high risk' could lead to 'high gain', risk became associated with negative outcomes, danger and loss. Cultural theory then identifies risk as a social-cultural construct (Brown, 2014) and explains risk in terms of how people understand and react to perceived dangers in their societies.

The equating of risk with danger in modern societies maligns those who engage in 'risky' pursuits and people/things which present a danger (Petersen & Wilkinson, 2008) and becomes a vehicle to apportion blame for unwanted outcomes (Lupton, 2006). Moreover, risk becomes a conduit for moral regulation because risks and risk-behaviour are undesirable, involving some intervention to avoid, minimise, correct or rectify (Peterson & Wilkinson, 2008). In relation to HBOC, medical discourse assumes risk avoidance is the norm and that people will take steps to reduce the risk of cancer developing. Saying no to RRS is thus seen as a form of risk-taking therefore women who refuse RRS may be seen as 'risky', creating a feeling of

individual and group uncertainty which may serve to exclude women from certain social groups and create a sense of non-belonging. Although breast/ovarian cancer is a 'natural' danger, in modern society risk is politicised into a moral concern (Brown, 2014) hence women who say no to RRS may be held accountable and blamed for their 'risky' behaviour.

Governmentality

The Governmentality perspective on risk in sociological theory draws on Foucault's theorising on societal governance strategies. Although the concept of risk was not extensively written about by Foucault, theories about power, self-regulation and control in modern society have been applied to sociological theories on risk and the role played by risk in the regulation of modern societies (Lupton, 2006). Foucault used the term 'governmentality' to refer to the relationship between 'governing' and 'mentality' (Zin & Taylor-Gooby, 2006) and the way modern states exercised control over the individuals to maximise the productive power of the population (Turner, 2008). Punishment and coercion were curtailed in favour of more subtle persuasive techniques which ensured social control through various societal institutions including medicine, the family, education and so forth (Gutting, 2008). Risks to the desired social order such as illness, poverty and unemployment were constructed as problems which could be solved through taking the appropriate actions (Lim, 2011). In the modern state however, although governments are responsible for identifying and distributing risks across society, risk avoidance is socially constructed as an individual duty (Maturo, 2012) hence risk thus becomes personal rather than societal, making it a moral technology which demands individual action (Lupton, 2013). Relating governmentality theory on risk to Western medicine reveals a connection between risk, medical discourse and risk reducing practices. In modern society, good health is perceived as a fundamental human right therefore health practices are constructed as inherently good (Crabb, 2006). Moreover, in the modern state

individuals are constructed as free-thinking, rational beings who make autonomous choices to better themselves and the wider society (Lupton, 2013), therefore responsibility for health is a requirement of good citizens (Peterson & Wilkinson, 2008). Since risk is now morally charged, it is a tool of power because once individuals are aware of risks, they are increasingly expected to self-regulate, conform to normalising strategies and reduce risk (Brown, 2014; Lemke, 2004). Women who conform to cancer risk management strategies by disciplining their risky bodies in accordance with medical discourse are doing 'the right thing', whereas those who do not, such as the participants in this study, may be considered morally lax (Lupton, 1995). Although not held personally accountable for their genetic material, women are held responsible for the actions taken or avoided to manage genetic risks (Hallowell & Lawton, 2002; Ilkilic, 2009).

To conclude this section, sociological theories on risk are primarily concerned with how risk has come to be a defining feature of modern societies. Of particular relevance to this study, changing perceptions of health based on risk perceptions for future disease are an inevitable outcome of advances in genetic testing in modern society (Maturo, 2012). Genetic testing for BRCA mutations permits a shift in the conceptualising of risk from abstract associations to something tangible and quantifiable. In modern medicine, the genetic risk of cancer represents a shift from disease as categorical (either the disease is present or it is not) to disease as dimensional on the continuum of risk. Disease as a pathological condition of the body is replaced with a reconstruction of disease as future impairment, or what Lupton (2006, p. 17) referred to as a "liminal category of wellness"; neither diseased nor fully well. However risk is in itself only a form of information and no test can definitively predict who will and who will not develop cancer.

Sociological perspectives on risk thus expose the irony of risk in modern society and in modern medicine. Attempts to calculate and control for risks to health are a key area of concern in modern medicine despite risk being by its very nature unpredictable, unknown and ever changing. In medicine, attention is focussed on presenting accurate, objective risk calculations and communicating these in such a way that individuals can make rational responses based on knowledge of the 'facts'. Within this discourse, personal, subjective and contextual meanings attributed to risk are unaccounted for, despite their importance in decision making. The next section expands this discussion by turning attention to risk communication in health care, especially in relation to the complex area of genetics.

Communicating cancer risk

Communicating information about cancer risk aims to inform individuals about risk management options whilst limiting anxiety and distress (Braithwaite, Emery, Walter, Prevost & Sutton, 2006). Communicating genetic risk attempts to reconcile personal perceptions of risk with objective assessments of risk (McInerney-Leo et al., 2006) so that clinicians can present data to individuals in a way which facilitates autonomous, informed decision making (Eijzenaga et al., 2014). However, despite the importance placed on autonomy and communicating risk in medicine, the best way of communicating risk is unknown (Ahmed, Willoughby & Edwards, 2012; Heshka, Palleschi, Howley, Wilson, & Wells, 2008) and the complex relationship between risk estimates, personal risk perceptions and risk communication is not well understood (Braithwaite et al., 2006; Klitzman, 2010; NICE, 2013; Wagner, 2011). It is therefore widely acknowledged that communicating information about risk is inherently complex and challenging (Bingham, 2012; Klitzman, 2010) and how risk is communicated impacts patient perceptions of risk and subsequent decision making in response to risk (Ahmed et al., 2012; Dauer et al., 2011; Wagner, 2011).

Genetic testing to determine cancer risk is underpinned by the premise knowledge of genetic status will reduce cancer worry, prevent unnecessary interventions and allow interventions to reduce risk of disease development (Esplen & Bleiker, 2015; Nelson et al., 2014). However, imparting information on cancer risk has been shown to both increase and decrease anxiety (Braithwaite et al, 2006; NICE, 2013), therefore people receiving information on risk incur benefits and losses depending on whether the result is favourable or not (Case, Andrews, Johnson & Allard, 2005; Nelson et al., 2014). Moreover, individuals receiving unfavourable results who experience an increase in anxiety may attempt to ignore the result in order to relieve inner tension (Case et al., 2005; Leydon et al., 2000) and hence may choose not to take part in suggested risk reducing interventions (Braithwaite et al., 2006; Turney, 2009).

The extremely complex nature of genetic information (Braithwaite et al., 2006; Case et al., 2005; Hoskins et al., 2012) and growing body of knowledge on cancer genetics poses particular challenges in communicating risk (Eijzenga et al., 2014; Evans & Howell, 2007). In order to assimilate the information given, an understanding of genetics and the mathematics of risk is required (Case et al., 2005), but such an understanding is argued to be out with the scope of most people (Klitzman, 2010; Swanson, 2002; Tamir, 2010). Statistical data is frequently complex and problems exist with health literacy (Hoskins, Werner-Lin & Greene, 2014) and the ability to access, interpret and act upon numerical and statistical data, is generally poor amongst the public (Turney, 2009) and indeed some health care professionals (Costa & Carneiro, 2011).

In medicine, risk is viewed as a rigorous estimation of probability based on statistical models hence personal perceptions of risk are considered a form of bias, tainted by emotional, personal and cultural experiences (Lupton, 2000). Personal over/under estimates of risk in comparison to the 'official' objective risk estimate are considered

confounding or distorting factors which may skew the data (Costa & Carneiro, 2011). Communicating risk may therefore be problematic because differences exist between scientific and lay understandings of risk calculations (Dauer et al., 2011; Paul et al., 2014). Although genetic counselling has been shown to improve accuracy of risk estimation in BRCA-associated cancer (Nelson et al., 2014), women frequently overestimate their personal risk of cancer compared with the objective risk estimate (Hoskins et al., 2014; Nelson et al., 2014) and perceptions of risk may remain unaltered or inaccurate even when knowledge of genetics increases (Borzekowski, Guan, Smith, Erby & Roter, 2013; Braithwaite et al., 2006; Heshka et al., 2008). This may occur because cancer anxiety can impact on the ability to assimilate genetic information (Hoskins et al., 2012) and because objective risk calculations do not take account of what people do with genetic information (Paul et al., 2014). Whereas biomedicine is concerned with diagnosing risk of disease, individuals are concerned with the impact of disease such as how severe it will be (Paul et al., 2014) and the impact on families (Hoskins et al., 2012) and children (Eijzenga et al., 2014). Hence the perceived impacts of are more important than the objective risk calculation in decision making around RRS (Hoskins et al., 2012; Tong et al., 2015; Witt, 2013).

Overall then, a number of subjective indicators influence risk perception which models for calculating and communicating risk are unable to account for (Dauer et al., 2011; Paul et al., 2014; Wagner, 2011). These include beliefs about inheritance and risk which may interfere with how risk information is assimilated (Finkler, 2000; Hoskins et al., 2012; NICE, 2013). The presence of a family history of cancer may lead a person to believe personal risk is very high, even when the objective measure calculates risk to be low/normal (Klitzman, 2010) hence the objective measure may be interpreted by the individual as 'wrong'. The calculated objective risk is therefore arguably irrelevant to what a person perceives their risk to be.

One reason for this may relate to how complex risk information is interpreted (Ahmed et al., 2012; Dauer et al., 2011). A difference exists between objective risk estimates based on statistical calculations and perceived risk estimates which incorporate individual experiences, cultural beliefs and societal practices (Davis, 2008). The public at large are generally limited in their understanding of genetics (Klitzman, 2010) hence may find it difficult to interpret uncertainty and ambiguous results (Werner-Lin, 2008), confuse probability with inevitability (Melzer & Zimmerman, 2002; Paul et al., 2014) and in the case of HBOC, erroneously believe penetrance to be 100% (Novas & Rose, 2000). Misconceptions about genetic data and statistical tests can also mean lay expectations are not in alignment with available knowledge regarding risk and certainty of disease development (NICE, 2013), which may lead to inappropriate use of risk reducing interventions (Klitzman, 2010).

Framing effects, or how risk is presented and communicated, also influences interpretation of risk (Ahmed et al., 2012; Dauer et al., 2011; Wagner, 2011). For example, the risk of death from an intervention looks very different when presented as the risk being 0.002 versus 0.001 compared with being presented as a 50% increased risk of death. In cases where risk estimates are identical, those framed as a gain, for example, 200 lives may be saved, are more likely to be accepted favourably than those presented as a loss, for example, 200 lives may be lost (Costa & Carneiro, 2011). Similarly, individuals may experience difficulties interpreting population risk in terms of personal risk. O'Doherty and Suthers (2007) illustrate using the following example: if a woman is identified as having a 60% lifetime risk of developing breast cancer, this means of 100 similar women, 60 will develop breast cancer, 40 will not. Whilst this information provides information on cancer development in populations, it does not provide the women with personalised information on risk. Surgery may confer for example, a 50% reduction in risk in high risk populations, but each individual person will either develop cancer or not hence the individual risk is 0% or

100% (Costa & Carneiro, 2011). Indeed Samerski (2006) argues the concept of personal risk is an oxymoron because by definition, statistical probabilities refer to the occurrence of events in a statistical population therefore it is simply not possible to tell an individual what they really want to know, which is if they will develop cancer or not and how severe the disease will be. Using O'Doherty and Suthers (2007) example, when a woman is identified as having a 60% lifetime risk of breast cancer, she becomes a member of the high risk group yet there is still no way of knowing if she will develop the disease. The high risk woman must therefore attempt to make sense of her personal risk of developing cancer using statistical data which ironically does not relate in any way to her personal situation.

It is evident therefore, a difference exists between expert and lay understandings of risk which statistical and decision making models are unable to account for. Whereas medical/genetic experts are likely to focus on 'real' objective risks and research findings, individuals experience risk as embodied owing to the potential risks to the body associated with certain procedures or events (Green et al., 2002; Ilkilic, 2009; Paul et al., 2014). Thus for women contemplating RRS, individual perceptions of risk and the importance attached to different risks are likely to influence decision making more than objective risk estimates and evidence-based findings (Hoskins et al., 2012). The significance of the risk is captured not by the risk itself, but by the meaning attached to the risk.

To sum, this literature review has examined various theoretical constructions of risk and the challenges presented by HBOC, cancer risk and effective risk communication. It can be concluded that personal perceptions and understandings of risk are influenced by a range of factors over and above the statistical models, risk estimations and outcome probabilities which underpin the medical pathway for RRS. It is clear the decision to accept or say no to RRS is highly complex, multifaceted and deeply

personal therefore the stories of those who say no to RRS add a valuable and necessary dimension to current understanding of how people come to make decisions about RRS when faced with a BRCA1/2 mutation.

Summary of literature review

This section has reviewed literature pertaining to several areas of particular relevance to this study. A review of research relating to breast/ovarian cancer, cancer predisposition and genetic testing outlined contemporary understandings of HBOC which underpin the medical pathway for managing breast/ovarian cancer risk. Current risk reducing interventions were then discussed and an examination of the potential physical and psychosocial impacts of such interventions concluded that RRS was associated with a number of potentially positive and negative sequelae. A critique of the concept of medicalisation suggested the experiences of women with BRCA1/2 mutations take place within a discourse of medicalisation which constructs risk, breast and bodies as targets for medicine and permits radical surgical interventions on healthy bodies. Finally, the concept of risk was examined from the perspectives of the natural and the social sciences with a focus on analysing how risk is presented, interpreted and understood at the level of both society and the individual.

The literature review demonstrated a wealth of research has been conducted on RRS for HBOC despite it being a relatively modern phenomenon. An emerging body of research which focussed on decision making around RRS was evident which appeared to focus primarily on two key areas: the identification and measurement of variables which may influence or predict decision-making in women facing RRS, such as age/parental status; and the potential physical and psychosocial impacts of RRS. The majority of studies have attempted to explore decision making around RRS and the impacts of RRS through quantitative means, with structured psychometric testing being the most common method employed. While these studies are helpful in

uncovering relationships between variables which may influence decision making and in identifying adjustment issues associated with RRS, they do not allow an in-depth exploration of the meaning of risk or understanding of how risk is understood and lived by women who carry BRCA1/2 mutations. No research was found which considered the experience of cancer in the woman's family and key moments in the lives of those facing RRS such as the confirmation of a positive family history, receiving a mutation-positive genetic test result and being offered and saying no to RRS. This was surprising given the focus of the research is an inherited condition which manifests itself through the diagnoses of parents, siblings and other family members. Additionally, little research was found which attempted to situate the decision to say no to RRS within the framework of Western medical discourse, despite the prominence of medicine in outlining how women high risk women should attend to their breast/ovarian cancer risk.

Hence, current research is unable to capture the human and very personal nature of deciding whether to accept or say no to RRS and fails to account for the entire range of influences on making decisions, conscious and sub-conscious, known and unknown, which are more than the sum of parts. Despite extensive research, current knowledge is limited in terms of understanding of how high risk women come to make what appear to be 'anti-health' choices within Western medical discourse by saying no to RRS, despite conclusive evidence of its effectiveness in reducing cancer risk. This research is an attempt to address this gap.

The following chapter introduces and discusses the methodological approach taken and its suitability for the study of high risk women who say no to RRS within the framework of Western medical discourse.

CHAPTER 3: METHODOLOGY

Introduction

This chapter describes and justifies the research approach taken to explore the experiences of women identified as high risk of developing breast/ovarian cancer who say no to RRS. RRSO is estimated to confer an 80% reduction in ovarian cancer risk and a 50% reduction in breast cancer risk while RRBM confers at least a 90% reduction in breast cancer risk in BRCA1/2 mutation carriers (Koskenvuo et al., 2013). Genetic testing and RRS are increasingly offered to high risk women (Hooker et al., 2014). This, in turn, may have led to an increase in the number of women experiencing complex psychological and emotional turmoil as a consequence of being labelled 'high risk' in terms of developing cancer (Lerman et al., 2002; Mahon, 2011) by the communal folklore of medicine.

Contextualising the research approach taken in this study

Advances in technology which enable the identification of women at risk for developing breast/ovarian cancer mean juxtaposition is created. Healthy women are advised to remove healthy breasts and ovaries against a backdrop of societal norms which dictate a particular female aesthetic and nurturing role as standard. However, for a group of women, the risk of developing cancer may not be sufficient to agree to surgery. These women are saying no to the removal of healthy tissue to deal with risk.

The women in this study were disease-free, yet were offered radical disfiguring surgery to remove healthy breasts and/or ovaries. The dilemma experienced for these women, is individual and personal. In order to understand and give meaning to these experiences it is necessary to be cognisant that when individuals make a decision about their personal lives, they do so within the confines of a particular discourse (White, 2004). Therefore, the decision to say no to RRS must be considered using a

research approach which allows the voice of these women to be captured within the context of the discourses used to make sense of their experiences.

Traditional empirical research approaches which use quantitative methods such as clinical trials and psychometric tests (Polit & Beck, 2013) are unable to illuminate why these women decided not to undergo RRS which could potentially prevent cancer and ultimately save their life. Quantitative approaches focus on ordering and rationalising lives (Denzin, 1989) and attempt to infer meaning about experience by analysing the number of responses to predetermined categories (Rowley, 2005). The control, identification and measurement of criteria which are assumed to influence the phenomenon under examination take primacy (Cohen & Crabtree, 2008). Within this context, personal influences which impact on experience may not be elicited if they do not fit with the predetermined assumptions of what is important. Szumacher (2006) contends traditional empirical approaches are limited in terms of understanding personal health decisions because of their quantitative nature and grounding in the dominant medical culture; such approaches are unable to capture the depth and complexity of women's experiences in relation to being identified as high risk of developing breast/ovarian cancer and saying no to RRS. These women needed a voice, prompting the need for a methodology which encouraged the women to tell their stories of how they experienced and perceived their bodies following a diagnosis of owning a BRCA1/2 gene mutation.

Frank's (1995) seminal work 'The Wounded Storyteller' contended that the experience of illness silences the voice of the individual but that this voice may be reclaimed through storytelling. Potts (2000) claimed the voices of women, in particular, were often silenced and made invisible. For this reason research pertaining to women should preserve their presence as central to the research to avert reducing women to objects of investigation. In keeping with this position, Crotser and Dickerson (2010)

posited that the complexity of cancer genetics added a challenging dimension to the creation of meaning about the experience of being identified as high risk of developing breast/ovarian cancer, adding the use of stories provided a means through which women may express and communicate meaning about the experience. Women's stories of experience in relation to HBOC are, therefore, an important source of personal and collective meanings attached to what is a common and present reality in the lives of women in Western society.

In contrast to empirical, quantitative approaches, qualitative approaches are rooted in the belief there is no single reality which can be discovered, but rather multiple, socially constructed realities exist (Denzin, 1989; Denzin & Lincoln, 2011) which can be studied to produce divergent inquiry (Lincoln & Guba, 1986). Moreover, qualitative methodologies and their underlying philosophical assumptions are appropriate for understanding the multifaceted and individual nature of personal health (Holloway & Wheeler, 2010), since they are based upon the belief that multiple realities exist within socially and mentally constructed individual realities (Bryman, 2004) and are applicable when the focus of the research is to increase understanding of poorly understood phenomenon (Creswell, Hanson, Plano & Morales., 2007; Polit & Beck, 2013).

Qualitative research methodologies are inherently interpretive as they aim to make meaning of specific experiences (Creswell, et al., 2007; Denzin, 1989; Denzin & Lincoln, 2011; Holloway & Wheeler, 2010; Schwandt, 2000). Research on social aspects of human existence has become increasingly concerned with meaning and interpretation resulting in a rising use of interpretive approaches (Harris, 2006; Sandberg, 2005). Harris (2006) further claimed no action, behaviour, trait or object was inherently good, bad or neutral, rather meaning was indeterminate until it was ordered through social interaction. Qualitative approaches take into account the wider

contexts of people's lives and broader social, political and cultural frameworks in which life and experience take place (Denzin & Lincoln, 2011; Holloway & Wheeler, 2010).

Broadly speaking, an interpretive research approach seeks to describe and understand experiences of individuals and set these within the context of social, cultural and historical influences (Holloway & Wheeler, 2010). The aim therefore is to create meaning rather than uncover the 'truth', since no universal truth exists (Denzin, 1989): only creation of meaning which is reflective of wider social, political, historical and cultural influences is achievable. In this study, the interpretive paradigm and underlying principles of research were utilised to enable an understanding of the experiences of high risk women which led them to say no to RRS, and place them within the context of historical and social constructs, as the experiences of these women can only be understood within the contexts of the worlds in which they live.

The interpretive approach

The ontological and epistemological assumptions which underpin the interpretive approach lie in the belief humans are constantly interpreting and re-interpreting the dynamic world in which they exist. The roots of the interpretive approach are often attributed to the work of German sociologist Max Weber (1864 – 1920) which has subsequently been developed by other phenomenologists. Many variations of the interpretive approach exist but shared by all is a phenomenological base which advocates humans are inextricably linked to their world through lived experience of that world (Sandberg, 2005). Hence there is no objective or universal real world, only a world as experienced.

Undertaking interpretive research requires the researcher to engage in a process of understanding the constructed realities of the research participants (Uzzell & Barnett,

2006) rather than impose meaning on the lives lived by others (Harris, 2006). An interpretative approach rests on inter-subjective construction of meaning and understanding (Angen, 2000) and emphasises interpretation and understanding are unavoidably bound and, understanding of social action may only be achieved by relating to an individual or group empathically (Holloway & Wheeler, 2010).

No 'truth' or single interpretation of reality can be judged as uniquely right or wrong because all claims to knowledge are open to multiple and differing interpretations and reinterpretations (Smith, 2008). Therefore, the researcher must denote the processes involved in interpretation which lead to different views being expressed (Harris, 2006). Thus, researchers taking an interpretive approach reject 'taken for granted' and 'common sense' notions of understanding the world and those who exist within it (Embree, 2009) and accept the reality of human experience is subject to an infinite number of variations and interpretations resulting in a "state of perpetual flux" (Oakes, 1977, p. 12). Knowledge is seen to be a construction of realities. Hence issues and events in societies are not unambiguous truths or facts but rather a collection of indistinct actions, events or problems which were aggregated by humans to create a social reality.

This rejection of an objective, knowable reality external to human consciousness is reflected in the belief that creation of social reality will always be coloured by historical, cultural, ideological and gender-based constructs (Sandberg, 2005). Importantly, it follows then if reality is never fixed but is socially constructed, then language itself is also socially constructed because language is created within the societies in which it exists. It may be argued, therefore, that language is intrinsically context-bound and lacks any fixed meaning. In other words, language creates rather than describes reality, resulting in multiple differing interpretations of what reality is (Haralambos & Holborn, 2000).

Underpinning any interpretive research approach is the assumption that the story told is able to be articulated in language which will be understood by both teller and listener/researcher. A central concept then in the interpretive approach is language as a conduit for social change. Language is the tool through which humans typify experience and meaningfully communicate it to others, resulting in shared understandings. Language is not a representational system which reflects or mirrors objective reality, rather it acquires its meaning through the ways it is socially defined and used in differing social situations and practices (Sandberg, 2005).

In this study, language is the medium through which high risk women meaningfully communicated their experiences regarding refusal of RRS. Davis (2008) and Seale (2001) identified that the language used to discuss breast and other cancers was constructed in such a way to endorse a particular approach to dealing with cancer, namely fighting and winning the battle against the disease. Additionally, Davis (2008) found breast cancer language incorporates personal, social and cultural meanings of disease. Therefore, the women's stories in this study reflect personal and societal views on how people with or at risk of cancer should speak, act and behave.

Allowing the women's stories to be shared in this way advanced an understanding of the experiences of saying no to RRS and situated the women's lived experiences within personal, social, cultural and historical influences. Moreover, the interpretive approach demanded the researcher interpret and re-construct the story making the process a biographical endeavour. Notably biographical methods are particularly suited to understanding lives of individuals and/or key periods within them (Surr, 2006; Jones, Glimmeyer & McKenzie, 2005). Thus, an interpretive approach encompassing a biographical method was appropriate in this study which aimed to create understanding of how high risk women came to say no to RRS.

The biographical method

The roots of the biographical method can be traced back to the interpretive paradigm developed by the Chicago School of Sociology in the 1920s, following research which was first to use biographical material to gain understanding of sociological issues, namely the lives of Polish migrants in Europe and America (Apitzsch & Siouti, 2007). Although then overshadowed by an upsurge of quantitative sociological research approaches, the biographical method began to increase in popularity again in the 1970s (Apitzsch & Siouti, 2007; Denzin, 1989), in part spear-headed by feminist writers who argued social enquiry into the human condition was not possible without the biographical method (Johnstone, 1999). Denzin's (1989) 'Interpretive Biography' further stimulated research using interpretive methods which aimed to illuminate an understanding of how individuals in society gave meaning to life and how researchers could capture those meanings in text.

The term 'biographical method' applies to a range of research activities including narrative, life histories, autobiographies, storytelling, interpretive biography, reminiscence and ethnography (Bornat, 2008). The diverse range of biographical methods which exist and the dynamic, personal and individualistic nature of biographical data add to the complexity of such a research process.

Bornat (2008) suggests a structure for all biographical approaches based on four key themes. Biographical data collection is a socially interactive process whereby researcher and participant engage in face to face dialogue. A focus on expression of self encourages the emergence of feelings and emotions which provide insight into personal perceptions and understandings of experience and create subjective knowledge. Data collected will have an obvious or implicit structure comprising a beginning and an end and which can be connected to prior theory. The accounts

created are contextual, that is, they are given meaning within frameworks of time and space and frameworks or agendas imposed by the researcher/interpreter.

These themes were important in this study as they reflected the desire to create a safe environment whereby women were encouraged to share deeply personal experiences and created an account which was reflective of personal reality. The nature of the situation; having a family history, being tested and then diagnosed with a genetic predisposition to cancer, being offered and then saying no to refusing RRS, meant the women's experiences were necessarily temporal as they were drawn into that sequence of events. Furthermore, dominance of medical and sexual discourses in Western society meant the women's experiences could not be divorced from the social world therefore it was necessary to situate them within it.

Irrespective of biographical method utilised, common to all approaches is the underpinning belief that an individual's biography is a social construct (Apitzsch & Siouti, 2007), and as such is influenced by inner personal knowledge and experience and prevailing cultural patterns of the time. Thus data obtained from the biographical method is viewed as historically, culturally and experientially bound and therefore open to multiple interpretations.

The overall aim of the biographical method is to explore ways in which humans construct understanding about their lives and to determine how they influence and are influenced by significant life events (Jones et al., 2005; Surr, 2006). Notably, Denzin's (1989) interpretive biography allowed the researcher to construct an understanding and represent the lives of those whose experiences do not conform to dominant societal perspectives (Williams & Holmes, 2005). Biographical methods construct documents of the "sociality of the individual" (Apitzsch & Siouti, 2007, p. 13) which allow analysis of how individual and societal influences impact on the creation of

identity. Apitzsch and Siouti (2007), further argued this makes biographical approaches particularly suited to studies concerned with women's experiences as biographies reveal aspects of personal and social influences on the construction of identity and gender. Further, biographical methods were particularly suited to this study because the experiences of women with a family history of breast/ovarian cancer were woven into stories and how they experienced and perceived their bodies. Denzin (1989) asserts that the point of origin for human life lies within the family; therefore biographical texts begin with a family history.

The participants in this study had witnessed family members suffer and sometimes die from cancer and had said no to RRS despite conclusive evidence of its effectiveness in reducing cancer risk. It is argued that this refusal was at odds with Western medical discourse therefore using Denzin's (1989) interpretive biography allowed the women's decisions to be considered in light of personal, social and cultural phenomena.

Interpretive biography

Key to the interpretive biographical approach is acceptance that societies, cultures and human experience can be inscribed and read as social texts. Denzin (1989, p. 11) defined interpretive biography as "(...) creating literary, narrative, accounts and representations of lived experiences. Telling and inscribing stories". In other words, human experience can be represented by symbolic statements.

The focus of interpretive biography is both on understanding how people give meaning to their lives, and how to capture these meanings in written, narrative and oral forms (Denzin, 1989). A central assumption underpinning the approach is the meanings people attribute to their lives and experiences are socially constructed and arise from interpretations of their own and others' behaviour. Although people live independently in society and create personal history, society influences how a life is

lived. The interpretive process is fundamental to this method as it provides the basis for understanding and making-meaning of the experiences of others as created in the biography (Denzin, 1989). Denzin (1989) further stated understanding is both a subjective and an inter-subjective, emotional process. That is, understanding involves drawing on both personal experience/the personal experience of others, and upon shared common experiences to construct shareable emotional feelings and cognitive understandings of the life experiences of another. Thus biographical research is “interventionist” (Denzin, 1989, p. 82) and is able to give voice to those who are unable to tell their story or who are denied a voice to speak.

Notably in Denzin’s approach, biographical data is gathered which captures “epiphanies or “turning point moments” which leave a mark on people’s lives (Denzin, 1989, p. 17). Epiphanies often relate to crisis moments and are fundamental to meanings people attribute to life and may have a positive or negative effect. Meaning is attached to epiphanies retrospectively as the experience is re-lived and re-interpreted in response to both the individual’s and others’ reactions to the experience. Epiphanies consequently alter meanings associated with past experiences and bear influence on individual identity. By studying epiphanies, the researcher is able to illuminate significant experiences in an individual’s life after which their life is irrevocably changed (Denzin, 1989).

Owning a genetic mutation and being advised there is a high risk of developing cancer is an experience for some women. This experience constitutes an epiphany moment since life changes forever as women face a future bound to the gene fault (Finkler, 2000). However, human experience does not occur in a vacuum, but rather the experience is situated within broader historical, cultural and institutional milieu of an individual’s life (Williams & Holmes, 2005). This supports Denzin’s (1989) view that a person’s life experience cannot be considered in isolation but rather is inextricably

interwoven into the entire fabric of the society, history and culture in which that individual exists:

No self or personal-experience story is ever an individual production. It derives from larger group, cultural, ideological and historical contexts. To understand a life, the epiphanies and self-stories that shape that life, one must penetrate and understand these larger structures. (Denzin, 1989, p. 73)

Epiphany moments are thus contextualised within social relationships and shared social and cultural norms (Jones et al., 2005), therefore a focus on epiphany moments attempts to make meaning of human experience within personal/individual and social/universal constructs. In this study, the epiphany moments of high risk women were contextualised against the backdrop of a health care system which espoused a particular discourse (Filc, 2004) and a society in which existed a communal folklore of what a woman 'is' and should look like. This approach valued everyday subjective experience as worthy of investigation and offered a unique insight into the experiences of women who had been identified as having a genetic predisposition to cancer yet had said no to RRS, and what this meant for them.

Methods of gathering biographies

Interpretive biography relies on oral and written accounts of experience which are interpreted and reconstructed to arrive at shared understanding and meaning. Essentially, a biography is a form of narrative study in which the experience of an individual's life is captured in text (Creswell et al., 2007). When a person's life is written about, the story told may attempt to cover the life completely or partially, depending on the experiences deemed as important to the story (Denzin, 1989).

Humans are essentially storytellers who use storytelling to make sense of life. (Moen, 2006). Moreover, stories about life are embodied as they are about bodies and are told through bodies (Blix, Hamran & Normann, 2012). Jarviluoma, Moisala and Villko, (2003) contended stories about personal experience cannot exist without

being gendered, as both teller and recipient of the story are embodied beings who interpret the story against personal and cultural perceptions of gender.

Denzin (1989) used the terms self-story, personal narrative and personal experience narrative to describe differing biographical forms aimed at gathering accounts of the lives of individuals. All share similarities and differences as alluded to by Denzin (1989, p. 47) when he stated “every term carries traces of other terms” and that the methods are themselves defined by each other in terms of difference. All are based upon an interpretive process which requires an individual to enter the emotional life of another and presupposes a life has been lived which can be studied, constructed, reconstructed and written about. Thomas-MacLean (2004) similarly stated analysis of people’s stories created understanding of the meaning of ill health and how people related the body to the social world. Cherry et al. (2013) reported exposure to the stories of women who had experienced types of RRS could help women considering it. Stories are essentially re-constructions of experience and interpretation of stories may advance health professionals’ understanding of people’s health related experiences (Holloway & Freshwater, 2007). This supports the views of Chapman (2002) who stated that the voices of those living with genetic conditions must be heard, as the debate arising from advances in genetic technology and testing continues.

Personal experience narratives

When a life is written about, it becomes a story of personal experience. In telling the story, the individual recounts events and experiences of past and present and may also anticipate future events yet to come (Liamputtong, 2009). Stories have a chronological dimension as the sequence of life events are recounted, and a non-chronological dimension which involves the construction of the whole story from smaller stories contained within (Jovchelovitch & Bauer, 2000). Frank (1995)

explained that people tell stories whereas narratives are created when stories are analysed. Narratives are thus storied ways of knowing and communicating (Riessman, 2006). During storytelling a teller engages in sharing and recounting an experience or event with a listener. A narrative is created when meaningful events are identified, organised and linked together to create order (Gray, Fitch, Fergus, Mykhalovskiy & Church, 2002). In research, narratives do not speak for themselves but rather require interpretation to be used as data (Riessman, 2006). The narrative constructed is situated within wider social and cultural contexts and reveals personal realities and social structures and processes (Gray et al., 2002).

In this study, the participants' stories became personal experience narratives. Simply put, personal experience narratives are stories people tell about personal experiences (Denzin, 1989; Dolby-Stahl, 1985) and describe events which exist independent of the telling, since the focus is on sharable experience. The participants told stories as a way of making sense of the world and communicating thoughts, feelings and experiences in relation to being identified as having a genetic predisposition to developing cancer and subsequent related events. The personal experience narrative was created by linking non-random events in relation to the women's experiences in a meaningful way.

Personal experience narratives are not primarily intended for sharing in social groups and may be told only to another listener, the sharing of which creates an emotional bond between the two (Denzin, 1989). Dolby-Stahl (1985) referred to this as the creation of intimacy: a bond between two equals who have the capacity and skills to share aspects of life experience with each other. It is the creation of intimacy which evokes a personal response from the teller and allows private folklore and personal meaning to be revealed. In the research setting, intimacy develops between the participant (as story-teller) and the researcher (as listener) through realisation the

experience is mutually understood (Williams & Holmes, 2005). Similarly, Riessman (2001, 2006, 2008) argued that a co-construction between the teller, the audience and the told always exists when gathering narratives. Data emerges from the relationship between the teller, researcher-as-listener and the context of the telling of the story (Riley & Hawe, 2005).

Personal experience narratives describe a set of events which generally follow a linear structure, that is, they have a beginning, middle and an end (Denzin, 1989). In this study, the life trajectory of the participants in relation to their turning point or epiphany moments up to completion of interviews provided the scope of the personal experience narrative gathered for data analysis. This described a causal sequence of connecting events as the participant's story unfolded through events in time.

Notably, personal experience narratives, or stories, are constitutive of reality and personal identity (May, 2012). Therefore these narratives draw meaning from common understandings which exist within a group and may also express the "private folklore or meanings" (Denzin, 1989, p. 44) and parts of the "inner life" of the story teller (Dolby-Stahl, 1985, p. 47). The examination of personal experience narratives allows the researcher to connect people's meaningful experiences to the society in which they live and to larger institutions which shape society through ideological practices (Denzin, 1989). Denzin (1989) advocated the analysis and subsequent interpretation of personal experience narratives was carried out using techniques of criticism. One such approach is Dolby-Stahl's (1985) literary folkloristic method, discussion of which and application to this study now follows.

Literary Folkloristic Methodology

This study required a methodology which allowed the participants to tell their stories in relation to how they experienced and perceived their bodies within the discourse of

Western medicine. The interpretive approach taken was consistent with social constructionist perspectives of society which advocate reality is a dynamic, socially constructed phenomenon and humans create social reality through their interactions with others and their resulting interpretations and understandings. The stories people communicate through language is one key way in which social reality is constructed by humans and represent the perceptions, values and experiences of the story teller. Moreover, personal experience narratives are literary productions because the teller continually engages in a process of selecting or rejecting what to say from an infinite number of possible things to say (Dolby-Stahl, 1989). Literary folkloristic methodology allowed the in-depth analysis of these stories, as told from the view point of the story tellers (in this case the high risk women who had said no to RRS) and created an understanding of the experience of being identified as owning a genetic mutation and saying no to RRS.

Dolby-Stahl's (1985) methodological approach contends narratives of personal experience sit within the genre of folklore. Folkloristic methodology seeks to both explain people's beliefs and practices in their own terms and to contextualise these views socially, culturally and historically (Oring, 2004). It has been argued that the study of folklore is central to our understanding of how human civilisation developed, since folklore study showed how cultures developed in the same way geology and palaeontology influenced Darwinian Theory (Trubshaw, 2003).

The term folklore is a widely defined but arguably often misunderstood term. Although frequently believed to concern uncorroborated myths, legends and fairy-tales, the term was first coined by the British historian William John Thomas in 1846, as a way of bringing together in one discipline the range of traditions, rituals, cultures and beliefs (lore) of different peoples around the world (folk) (Simpson & Roud, 2000).

The United Nations Educational, Scientific, and Cultural Organisation (UNESCO)

defined folklore as:

Folklore (or traditional and popular culture) is the totality of tradition-based creations of a cultural community, expressed by a group or individuals and recognized as reflecting the expectations of a community in so far as they reflect its cultural and social identity; its standards and values are transmitted orally, by imitation or by other means. Its forms are, among others, language, literature, music, dance, games, mythology, rituals, customs, handicrafts, architecture and other arts (UNESCO, 1990, p. 239).

Alan Dundes, a leading folklorist credited with establishing folklore studies as an academic discipline, proposed a simplified definition of folklore as being about 'form – function – transmission' (Trubshaw, 2004). Folklore was traditionally transmitted orally between members of a folk group although more recently electronic media and forms of communication also transmit folklore (Trubshaw, 2004). The transmission of folklore is contextual and establishes group identity through shared meanings and understandings which are reflective of larger shared understandings of the group but which may be unstated (Trubshaw, 2004). Although folklore is originally created by group members, it ultimately serves to define and perpetuate group membership by excluding those who lack the shared understanding. For these reasons, Trubshaw (2004) goes on to suggest Dundes' definition be amended to 'form – context – transmission' to reflect the complexity and contextuality of modern society. However, not all communication transmitted between groups and between people would be considered folklore, therefore distinction must be made between what folklore is and is not. For Trubshaw (2004) the crucial difference was folklore was unedited or unmediated whereas other forms of communication such as those transmitted by the mass media and large organisations, governments and so forth was not. This viewpoint is in keeping with the earlier work of Hufford (1998, p. 301) who defined folklore as "unofficial culture" in contrast to "official culture" which was associated with an office, post or other bureaucratic position. Comparison is made between this and Dolby-Stahl's (1985) 'communal folklore' which described collectively held views in

populations or societies which are transmitted through informal communications and customary stories. Common to all is acknowledgment of norms which are collectively but unofficially held by members of a group or society and which are communicated and perpetuated through membership.

Hufford's (1998) definition of unofficial versus official culture, highlights the description and interpretation of reality as transmitted through folklore and non-folklore communication is a political process in which social relations related to power and authority are influenced by dominant discourses. The Marxist sociologist Gramsci (1971) used the term 'hegemony' to describe the rule of one class over another by using coercion or more subtle persuasion to ensure the ruled class accepted the ideologies, rules and laws of the ruling (hegemonic) class. Again, this is similar to Hufford's concept of official culture and is more likely to disperse 'edited' or 'mediated' communication to promote compliance. Similarly Trubshaw (2004) linked folklore to political activity as it was a means of transmitting poems, songs and stories which could contest the hegemony and promote the emergent ideologies of other groups.

The folk of contemporary folklore are described by Dundes (1980, p. 6) as:

(...) any group of people whatsoever who share at least one common factor. It does not matter what the linking factor is – it could be a common occupation, language or religion – but what is important is that a group formed for whatever reason will have some traditions which it calls its own.

Dolby-Stahl (1985) expanded the concept of folklore in her literary folkloristic methodology to distinguish between 'communal' and 'private' folklore: communal folklore represented the traditional stories and beliefs collectively held by the wider population, and private folklore represented what was exclusively shared by a sub-group of the population and which was not necessarily publicly revealed. Private folklore is revealed when intimacy is created between the willing participant and the researcher-as-listener during the interview process: "the teller teaches the listener to know him better" (Dolby-Stahl, 1985, p. 51). For Dolby-Stahl, exploration and analysis

of private folklore contained within personal experience narratives was fundamental to creating meaning and understanding of the lives of people. Like Denzin (1989), Dolby-Stahl (1985) acknowledged the challenges associated with understanding and creating meaning from the written and oral texts of others, since there can be no permanence of the original text: as soon as words are spoken, they disappear. At most, the researcher can retain a written or taped copy of what was said for later analysis and interpretation.

Central to Dolby-Stahl's methodology is the concept of the "informed listener" (1985, p. 54). It stands to reason that any individual can listen to the story of another and offer a response to that story. This response may be valuable and meaningful to understanding the story, especially if the listener shares cultural commonalities with the teller. However, Dolby-Stahl (1989, 1985) argued the contribution of the informed listener was potentially more valuable. An informed listener is one who not only shares aspects of the teller's folk group, but also uses literary theory to critically deconstruct the text, discover hidden clues and identify themes and motifs, and crucially, takes full responsibility for translating what was heard (Dolby-Stahl, 1985). This is of great importance, as in keeping with Denzin (1989) it is argued that one can never accurately replicate a life or life experience, therefore the focus is on the text created by the individual and not the individual per se. On hearing the story, the listener must create meaning along with the storyteller, and the listener is responsible for their response to the story. Listening to the story is thus a creative act during which the listener brings their own store of personal and cultural perspectives to bear on the interpretation (Dolby-Stahl, 1985).

Dolby-Stahl (1985) contended the most important feature of any interpretive project was the reader was able to see how the story was interpreted in the way it was. It is essential therefore the researcher-as-listener demonstrates how responses evolved

and how interpretations were arrived at. Literary theory is used to critically deconstruct the personal experience narratives to identify themes, attitudes and allusions reflective of societal expectations which influence how a life is lived and experienced (Williams & Holmes, 2005). Analysis of biographical data therefore requires an approach which makes sense of the teller's life and understands the life from both a private and public perspective.

Biographical analysis

The methodological approach taken in this study combined Denzin's (1989) interpretive biography with Dolby-Stahl's (1985) literary folkloristic methodology to provide a method for gathering, reading and interpreting participants' personal experience narratives. This meant analysing the participants' personal experience narratives for meanings of experience which could then be interpreted using the techniques of literary criticism. However, neither Denzin (1989) nor Dolby-Stahl (1985) outlined any particular method for writing and reading biographical texts exists, rather it was argued a range of literary techniques may be utilised to analyse and communicate experiences connected to the life of the individual.

Wide variation in biographical methods (Bornat, 2008) coupled with differences in how researchers employ the concept of personal narrative (Thorne, Kirkham & O'Flynn-Magee, 2004) means diverse strategies of data analysis are associated with interpretive approaches. However, common to all is the requirement to construct texts for further analysis by organising the texts/data, creating field notes and/or choosing particular sections of the text for detailed inspection (Riessman, 2006). Denzin (1989) acknowledged all data analysis techniques had inherent weaknesses in them since the study of human experience was inevitably fraught with contradiction and ambiguity. Data analysis is an intuitive process when conducting interpretive biographical research therefore specific analytic techniques are rarely prescribed nor

the steps taken clearly articulated (Bryman & Burgess, 2002). Thus the process of data analysis in interpretive studies eludes a methodological orthodoxy and instead employs techniques which fit best with the research aims and overall epistemological and ontological assumptions of the study.

It is generally agreed the most appropriate tool for analysing biographical data is that which suits the focus of the research (Surr, 2006), addresses the study aims (Creswell et al., 2007) and allows the researcher to make sense and create understanding of the participants' significant life experiences (Liamputtong, 2009; Thorne et al., 2004). The favoured approach to data analysis will reflect the researcher's epistemological assumptions, values and cumulative experience (Dolby-Stahl, 1985). Thus there are no fixed or mandatory procedures associated with biographical analysis, rather justification for the particular data analysis approach taken must be provided. Bornat (2008) however cautioned against over-explaining analytical procedures when undertaking interpretive biography as this suggests the researcher (as interpreter) is in a position of authority and control which can serve to eclipse the participants' responses.

Consensus exists that data analysis in biographical research is an intuitive process (Bryman & Burgess, 2002) which involves separating the chronology of events from the meanings individuals attach to them (Bornat, 2008). The focus of data analysis remains on uncovering meaning of significant experiences of people and relationships between experiences (Gültekin, Inowlocki & Lutz, 2003). The researcher sets out to make connections between the participants' past, present and future experiences and reveal influences and contexts which may have shaped experience which participants may or may not be aware of (Bornat, 2008).

The interpretive biographical approach taken in this study is dependent upon analytic induction, a process which seeks understanding of phenomena which illuminates characteristics, patterns and structures in a theoretically useful way (Thorne et al., 2004). This allows understanding of an individual's inner world to be created and shared with those outside that world (Fraser, 2004). Notably, this analysis reveals knowledge of experiences or events considered threatening or traumatic to people (Gültekin et al., 2003) such as those associated with being identified as high risk of developing cancer. Additionally, analysis may include reference to folk sayings and proverbs (Aronson, 1995) and reveal aspects of the participants' private and communal folklore (Dolby-Stahl, 1985). Data analysis is a complex process however as references to such events and experiences are threaded throughout the text, revealed in various ways, hidden or glossed over, therefore the analysis seeks out explicit and hidden meaning in the text (Bornat, 2008).

In this study, the aim of data analysis was to generate understanding of the participants' experiences of being identified as high risk of developing breast/ovarian cancer and saying no to RRS in order to create knowledge which may be applied in a theoretically meaningful way. Additionally, the study aimed to understand the public and private folklore of the women so that their life experiences could be understood within the context of personal, social, cultural and historical influences. Narrative analysis was particularly suited to this study as it allowed the systematic study of personal experience and meaning (Riessman, 2001, 2005). Narrative analysis facilitates a focus on events, emotions, feelings, meanings and explanations contained within the participants' stories (Liamputtong, 2009), and so makes visible what was important about an individual's experience. Narrative analysis can make-meaning of turning point moments (Riessman, 2001, 2005), or what Denzin (1989) referred to as epiphanies, which change an individual's biography.

Burck (2005) argued that narrative analysis illuminates ways in which people construct themselves within groups and societies and how people position themselves in relation to dominant notions of self. Riessman (2001, 2006) described this as a way in which individuals construct and claim personal identity. The participants' stories in this study were analysed from the perspective of how personal identities were formed against a backdrop of dominant social and cultural discourse and ideologies.

Narrative analysis is an umbrella term for various theoretical approaches to interpreting stories (May, 2012; Riessman, 2006; Stephens & Breheny, 2013). The approach taken is dependent upon the study aims and theoretical orientations of the researcher (Shi, 2008). However, all approaches provide a way of systematically analysing personal experience narratives and share a common tactic: the analysis takes the stand point of the storyteller as its starting point (Riessman, 2001, 2005, 2006; Riley & Hawe, 2005). Riessman (2005, p. 2) contends different approaches to narrative analysis reflect whether the study focus is on "the told" or "the telling" and no one approach is superior to another. Approaches to interpreting stories thus differ on questions relating to why and how stories are told (Riley & Hawe, 2005). Riessman (2001, 2005) described various approaches but highlighted the approaches are not mutually exclusive and different approaches may be combined in one study.

In this study, Riessman's (2005, 2006, 2008) thematic narrative analysis informed the data analysis process. Thematic analysis is the most commonly utilised method of narrative analysis and is frequently used in health care research to increase understanding of people's experiences of illness and disease (Riessman, 2005, 2008) and has been used widely in folklore studies (Riessman, 2008).

When using thematic analysis, the researcher seeks ideas, themes and clues from within the participants' stories and compares these across stories. Importantly, rather than breaking the personal experience narratives down into coded segments, thematic analysis keeps the story intact and interprets and compares each participants' story as a whole. The sequence of the narrative is preserved and large sections of the text are presented in some detail to illustrate themes (Riessman, 2008). Comparing the narratives against each other as a whole reveals broader contexts which shape personal experience. In contrast to other forms of narrative analysis, thematic narrative analysis focuses less on form and narrative devices used to construct stories and more on content and themes (Riessman, 2005, 2008). Thus the focus is on what was said not how it was said or the purpose of telling. A focus on content produces a chronological account of experience which is then evaluated for the meaning attached to events and experiences (Elliot, 2005).

Language is viewed as a resource for communicating experience rather than the primary object of investigation, maintaining the focus on the personal experiences of the storytellers. Nonetheless, particular word choices, metaphors and references to folklore may be exposed and investigated in terms of their function within the text and the meanings they carry (Riessman, 2008). Thematic analysis therefore facilitates a focus on the told which comprises reports of events and experiences and how these were lived and experienced (Riessman, 2008). From this, an awareness of the individual in society is gleaned which allows an understanding of social and cultural groups and structures and relationships between them (Elliot, 2005). This is in keeping with Denzin (1989) who asserted that to understand a life, consideration must be given to the wider social and cultural structures which shape human experience.

In thematic analysis, data is interpreted in light of thematic elements developed by the researcher in accordance with the research aims, a priori knowledge, emergent theory

and the data produced (Riessman, 2001, 2008). Providing explanation of and rationale for chosen categories allows the researcher to exhibit transparency in the research process and affords the reader an opportunity to reflect on the logic underpinning the analysis (Fraser, 2004). This is an important aspect in this study, because it was reasoned it was incumbent on the researcher to be transparent throughout the research process and provide rich, substantive accounts of participants' experiences which demonstrated how a particular interpretation was arrived at.

Thematic narrative analysis has been criticised on the basis it assumes a common language exists which will be understood by all (Riessman, 2006). Such criticism could however be extended to any analytic research approach as all involve language in all its ambiguity and instability. Hence, the approach taken in this study acknowledged the challenges inherent in the study of human experience but contended accepting and negotiating these was integral to understanding the experiences of the participants. The application of narrative analysis in this study is described in Chapter 4.

In summary, analysis of personal experience narratives reveals knowledge of and about the individual concerned. However, biographical researchers are only ever able to "create the subject in the text that is written" despite the subject (person) having lived a 'real' life with 'real' experiences (Denzin, 1989, p. 23). The participants in this study were real people who existed independently of the text, but for the purposes of this research, the participants were created as subjects in text within particular discourses and historical periods. The subjectivity of personal experience narratives used to capture the participants' biographies was acknowledged as strength because it is this subjectivity which creates human reality (Denzin, 1989). The participants told stories of their lives and their experiences of being identified as high risk of developing

cancer and saying no to RRS. However, the stories told were one of a number of stories which could have been told hence biographical methods used to construct lives in text are literary productions and accordingly, are open to multiple, differing interpretations. The subjectivity of personal experience narratives therefore also lays the approach open to criticism because of their ambiguous, temporal and shifting nature. Accordingly, the next section discusses the ambiguous nature of truth and how this was negotiated in this study.

Truth, validity and evaluation in interpretive research

Designing and undertaking effective and meaningful research is the goal of all researchers (Angen, 2000; Holloway & Wheeler, 2010) therefore it is essential all research irrespective of the approach taken presents the findings from research and the subsequent interpretation of data in some credible way (Cohen & Crabtree, 2008; Major & Savin-Baden, 2010). The overall aim then of all data analysis is to transform raw data into a clear and credible account of the research findings (Fossey, Harvey, McDermott & Davidson, 2002; Liangputtong, 2009). Extensive epistemological debate exists as to the most useful and appropriate way to achieve this, notably in relation to what constitutes 'the truth', 'truths' and 'truthfulness' (Major & Savin-Baden, 2010) and whether or not research is able to identify a true version of reality (Cohen & Crabtree, 2008; Smith, 2008).

Traditional criteria for evaluating research are rooted in the positivist paradigm and presuppose an objective measurable reality exists independent of the interests of the researcher (Cohen & Crabtree, 2008; Denzin & Lincoln, 2011). The standard conventional criteria used to assess the quality of the research are validity, reliability and generalisability. Internal validity is the extent to which a data collection instrument measures what it intends to measure while external validity relates to how far the study results can be generalised to other populations (Polit & Beck, 2013). Reliability

refers to the consistency of an instrument and is a measure of how well the instrument produces the same or similar results if administered under the same or similar conditions (Parahoo, 2006). Establishing validity and reliability are important factors in generalising the study findings: drawing broader inferences from particular observations through the demonstration of cause and effect relationships. Traditional research approaches attempt to produce an objective description of reality in order to make predictions about how individuals will act in that reality, or respond to a particular intervention, on the basis consistency of response (Cohen & Crabtree, 2008). In contrast, the methodological approach taken in this study was grounded in the belief humans are constantly interpreting and re-interpreting the dynamic world in which they exist in order to make meaning of experience. The approach taken was not preoccupied with a search for '*the truth*' thus traditional criteria for evaluating research were not applicable. The interpretive approach utilised in this study rejected the notion of an objective, knowable reality external to human consciousness and instead argued multiple realities exist within socially and mentally constructed individual realities. Hence the experiences of high risk women who say no to RRS were considered in light of social, cultural and historical influences which shaped human experience and consented to certain ways of speaking and behaving. Rather than searching for objective truths and explanation, the focus of this research was on understanding and meaning-making (Denzin, 1989; Dolby-Stahl, 1985).

Denzin (1989) claimed that positivist epistemologies directed the research process in a search for absolute truths and turned the subject of the biography into an object. However, humans are not objects and are exposed to a wide range of influences on behaviour (Crossan, 2003). Research carried out in the interpretive paradigm presupposes reality is fluid and co-constructed. Knowledge is gained through negotiation between the researcher and the participants (Cohen & Crabtree, 2008; Lincoln & Guba, 1986). In this study, distinction was drawn between objective

markers of experience and the subjective meanings attached to them by individuals (Denzin, 1989). Undertaking biographical research requires acceptance of the ambiguous nature of truth and reality notwithstanding real people living real lives with real experiences. Denzin (1989) explained this stance by referring to different standards of autobiographical truth. Facts are events which occurred (or which will occur) and are able to be corroborated, such as being identified as owning a genetic mutation which increases a woman's risk of developing breast/ovarian cancer. Facticities are how these facts were lived and experienced by individuals, for example, the subjective experiences of women diagnosed with owning a genetic mutation. Fiction is a narrative account which deals with facts and facticities, real or imagined, and may therefore be true or false. A true fiction is one which is faithful to facts and facticities attempting to represent these in accordance with how they existed and were experienced, creating verisimilitude (Denzin, 1989): demonstration of the appearance of truth (Major & Savin-Baden, 2010). Accordingly, the personal experience narratives of the women in this study represented a version of reality which appeared to be faithful to facts and facticities and which reflected what was important to how the experience was constructed, understood and made sense of at the time.

Personal experience narratives are "temporal productions" (Denzin, 1989, p. 73): stories of the past, told in the present and only one of a number of stories which could have been told. Moen (2006) similarly discussed the fictional nature of personal experience narratives, drawing distinction between the lived life and the life experienced. The lived life comprises the events which occurred and are able to be corroborated. A life experienced comprises feelings, values, sentiments, thoughts, inflections and all forms of meaning known to the individual whose life it is. Capturing the life told creates a personal experience narrative shaped by cultural conventions inherent in telling the story, social contexts and audience responses (Moen, 2006).

Another distinction exists between the story told and the story heard (Denzin, 1989). The story is told through language, itself a symbolic, metaphoric and changing medium which influences how the story is shared and heard. Different perspectives and interpretations are brought to bear upon the story from the differing biographical positions of teller and listener. Differences between teller and listener merge to form a collective version of the story told, at a point in time. In this sense, just as there is no one truth about the lives of others, similarly there is no one truth or single interpretation researchers are able to make regarding the life experiences of others (Denzin & Lincoln, 2011).

It may equally be argued empirical/scientific data are open-ended temporal productions. For example, as recently as September 2012, scientists uncovered new 'facts' about breast cancer which were previously unknown (Cancer Genome Atlas Network, 2012). Breast cancer is now 'known' to comprise four genetically distinct types, one of which shares genomic similarities with a particular type of ovarian cancer. This new information has been interpreted in Western medicine as knowledge likely to re-shape scientific understanding of cancer, paving the way for more therapeutic interventions and cures. The revelation of new knowledge and subsequent contemporary understanding about cancer and treatment accentuates the shifting nature of science and the impermanence of scientific truths. Indeed the Human Genome Project itself is evidence of the impermanence of scientific knowledge *par excellence*, as knowledge of the causes of disease prior to the mapping of the human genome is now called into question and re-examined in light of new genetic information. This in itself is not surprising, nor is it unexpected. It stands to reason treatment for cancer will change as scientific discoveries continue to reveal previously unknown information about the disease and its manifestations. The key point however remains: no permanent, time or value-free criteria exist for determining what knowledge is true (Denzin, 1989; Denzin & Lincoln, 2011) and no special

research methods exist which automatically and inevitably lead to 'the truth' (Smith, 2008).

The line between fact and fiction is blurred in biographical texts and true stories are those which are believed in (Denzin, 1989). Any storyteller can construe facts about his or her life and no-one can know what is true and what is false on every occasion. All storytellers chose what to divulge and what to keep hidden (Dolby-Stahl, 1985, 1989; Thorne et al., 2004) therefore the personal experience narratives of the participants in this study reflect a personal understanding of reality. Social, cultural and ideological conventions guide what people in society feel able to say and not say at any given time, hence what is presented is an edited version of reality (Denzin, 1989). However, what is shared is what was important to how experience were constructed and what sense women made of experience at the time. If the storyteller deliberates that their experience was real and believes in its existence, then the story told is authentic. The importance of the story is that it describes the *experienced reality* as opposed to the *real reality* (Bate & Robert, 2007). This is the essence of the interpretive approach.

For Denzin (1989) and Dolby-Stahl (1985, 1989), preoccupation with validity, reliability and generalisability is set aside in favour of a concern for meaning and interpretation. In this study, interpretive biographical techniques of literary criticism were used to understand participants' subjective experiences rather than accumulate facts about their lives (Green & Thorogood, 2009). Denzin (1989) said that subjectivity creates rather than distorts reality. Similarly, Riessman (2001, p. 696) affirmed that subjectivity is a strength of the interpretive approach rather than a weakness: "the approach does not assume objectivity; rather, it privileges positionality and subjectivity". Blix et al. (2012) confirmed that temporality and impermanence of

personal experience narratives were not problematic but rather an opportunity for obtaining a deeper understanding of the human condition.

The interpretive approach has been criticised on the basis it lends itself to an 'anything goes' approach to research and suggests any claim to knowledge is as worthy or valuable as any other (Smith, 2008). Interpretivists however counter-argue all any individual can do is describe and justify knowledge on criteria which are historically and temporally shifting. For both researcher and participant, the story is constructed around the interests and intents which make the story meaningful. Consequently it is not possible to achieve a neutral or an unbiased opinion since humans are unable to negate or eliminate a priori knowledge and influences from past experiences (Smith, 2008).

From the above discussion, it is evident a key challenge in this study was reconciling the desire to capture, understand and make-meaning of the experiences of high risk women who said no to RRS with recognition that there can never be one true or precise representation of a woman's life. For researchers using biographical analysis, the tension between relativism and material reality must be addressed. If one accepts biographical methods are able to capture and represent the life of the person in text, how does the researcher deal with the lack of any objective truth or reality and present findings which will be accepted and evaluated as credible and worthwhile?

Attempts to define evaluation criteria more in keeping with epistemological assumptions underpinning qualitative research approaches have been made. In their seminal work, Lincoln and Guba (1985, p. 290) acknowledged the need for qualitative research findings to be presented in a credible and meaningful way: "how can an inquirer persuade his or her audience that the research findings of an inquiry are worth paying attention to?" Lincoln and Guba (1985, p. 299) argued traditional

positivist criteria for evaluating research were based on assumptions of “naïve realism”, a belief in unchanging, tangible truths which served as benchmarks against which study findings could be reliably measured against. However as previously argued, the theoretical standpoint taken in this thesis contended what constitutes knowledge, and by extension ‘the truth’, is impermanent and only ‘true’ within the historical, cultural and societal contexts in which it was produced and maintained. This study was a study of human experience. It did not seek to make context-free truthful statements about experience or seek to identify cause and effect relationships which could allow the findings to be generalised. Rather the study aimed to provide a credible account of how the participants came to say no to RRS by offering interpretations of how multiple, interacting factors, events and processes shaped experience. Traditional ways of claiming knowledge which are based on objectivity and freedom from bias in research studies were thus incongruent with the methodological approach taken in this study.

Lincoln and Guba (1985) proposed alternative criteria to validity, reliability and generalisation for demonstrating rigour and trustworthiness in qualitative inquiry. In particular, Lincoln and Guba (1985) rejected the value of validity: if no one true reality exists, there can be no claim to ever completely accurately represent someone else’s reality through the research process. Furthermore, since reliability is a precondition of validity, it follows the concept of reliability is equally extraneous in qualitative inquiry (Butler-Kisber, 2010). Instead, Lincoln and Guba (1985) proposed the concept of ‘trustworthiness’ in qualitative research which has four main criteria. Credibility is used in place of internal validity and refers to the level of congruence between the researchers’ findings and the participants’ realities, or the truth value of the research. The concept of transferability is used in place of external validity and relates to the degree to which the study findings can be applied to other contexts or other populations. Reliability is replaced by dependability which concerns evidence of how

likely the study would yield the same or similar findings if repeated on a similar population in a similar environment. Confirmability is suggested in place of objectivity and is a means by which the researcher demonstrates the findings were produced by the focus of the study and not as a result of any biases on the researcher's part.

Lincoln and Guba (1985) also suggested a range of techniques which could be utilised to demonstrate rigour and establish the trustworthiness of the research. Ways of increasing credibility include member checking, peer review, negative case analysis and prolonged engagement in the field. The use of thick description to present the findings in such a way so others can determine if relevant to their setting facilitates transferability. For dependability and confirmability, the use of an audit trail which clearly links the findings and interpretations to the original data sources and ensures the researcher's processes are logical, traceable and acknowledged is advised. However, others have argued such 'checks' on accuracy of data interpretation still assume an objective reality exists which can be accurately measured to uncover truth and are therefore incongruent with an interpretive approach (Cohen & Crabtree, 2008). Similarly, Morse, Barrett, Mayan, Olsen & Spiers (2002) argued such concepts were not relevant to all types of qualitative research including feminist approaches and those utilising critical theory, such as in this study, where the researcher's interpretations form part of the data.

Further work of Lincoln and Guba (1986, 1989) sought to extend the debate on evaluative criteria for qualitative inquiry. It was acknowledged the concept of trustworthiness, and its accompanying criteria, were initially devised to parallel conventional criteria in the absence of other measures. Although trustworthiness was proposed as an improvement on the traditional criteria, Lincoln and Guba (1986, 1989) nonetheless acknowledged the inherent misnomer in devising new criteria which were analogous to the rejected positivist criteria. Devising equivalent criteria

suggested the issues of importance were the same for both approaches and diverted attention away from devising suitable interpretive alternatives. To this end, Lincoln and Guba (1986, 1989) proposed an additional criterion of 'authenticity' as a means of demonstrating the quality of qualitative research. Holloway & Wheeler (2010) summarised the components of authenticity thus: fairness refers to the extent to which a range of different realities, or constructions of reality, are presented by the researcher. The research findings should raise consciousness of and develop new insights into the phenomenon under investigation (ontological authenticity) and increase understanding and appreciation of the views of others (educative authenticity). Authentic research also stimulates action (catalytic authenticity) and empowers others to act (tactical authenticity). Thus the concept of authenticity appeared to address issues of importance in qualitative research such as understanding of different realities/multiple interpretations, mutual understandings, ethical research and empowering others, and therefore was more responsive to the needs of qualitative researchers (Fossey et al., 2002). However, despite extensive theorising by Lincoln and Guba and many others, no one set of criteria with which to gauge the quality of qualitative research has yet been devised (Fossey et al., 2002; Denzin & Lincoln, 2011; Holloway & Wheeler, 2010). Widespread debate remains evident in the literature regarding the value of specific criteria for evaluating utility and worth of interpretive and other types of qualitative research. The drive for a single set of evaluative criteria suggests a uniformity amongst qualitative approaches which does not exist.

The use of criteria relevant to qualitative research however, facilitates a focus on exploring human experience in relation to social, cultural and historical contexts rather than objective scientific data. There is general agreement further critique of what constitutes quality criteria in qualitative research is needed (Fossey et al., 2002; Guba & Lincoln, 1994). However, irrespective of the labels attached, researchers must

demonstrate their research has truth value which requires consistency in the language, concepts and methods used (Fossey et al., 2002; Holloway & Wheeler; 2010). To this end, a general consensus on fundamental criteria for evaluating interpretive research exists (Cohen & Crabtree, 2008) which informed the approach taken in this study.

The research should be ethical, important and be clearly and coherently articulated. Rich, substantive accounts of participants' experiences should be presented which illuminate subjective meanings and reflect multiple ways of seeing a phenomenon (Cohen & Crabtree, 2008). There must be transparency throughout the research process and discussion of issues such as the positioning of the researcher and power relationships must be made explicit (Caelli, Ray & Mill, 2003). The interpretive lens of the researcher must be visible and accessible during the course of the research (Thorne et al., 2004) and researchers must demonstrate self-reflection and explain how a particular interpretation was gleaned (Angen, 2000; Holloway & Wheeler, 2010). The researcher must also take steps to outline his or her stance in relation to the participants, methodology and method and demonstrate honesty and consistency between methods and researcher (Fossey et al., 2002; Major & Savin-Baden, 2010). In this study, these steps have been addressed in several key ways: by making explicit reference to these criteria when describing and justifying the study design and processes; by presenting the participants' stories in their own voice through the use of substantive accounts of experience and thick description to support the interpretations offered and by the inclusion of a reflexive account (see Chapter 7) which discusses the ways in which the researcher's subjectivities may have influenced the research process. This study therefore is presented as a credible account of the experiences of high risk women who said no to RRS and the meanings the women used to make sense of their experiences.

Chapter summary

The interpretive approach taken in this study provided a contextualised narrative of the life experiences of the study participants. It was evident the women were folk and belonged to many different folk groups. They were mothers, sisters, patients, daughters, friends, colleagues, neighbours, bosses and employees, to name but a few. Additionally, as women in Western society, they were subject to communal folklore surrounding the female body, the breasts and ovaries, cancer and death and dying. In particular, the women in this study had said no to RRS despite its effectiveness in reducing cancer risk in high risk populations and as such shared a private folklore which contributed to their decision to say no to surgery.

The methodological approach taken acknowledged every interpretation contains subjective elements thus neither researchers nor participants are able to escape personal beliefs and ideologies, social circumstances and lived experiences. Interpretation therefore is a social and political endeavour rather than a purely cognitive act (Schwandt, 2000). The most important feature of interpretive research is not whether the researcher accurately recounts the person's life experience, but rather the reader is able to see how the story was interpreted in the way it was (Dolby-Stahl, 1985). It is essential therefore for biographical researchers to make sense of the lives of participants whilst recognising the resulting texts will be reflective of personal ideologies (Williams & Holmes, 2005). Analysis of biographical data therefore required an approach which made sense of the teller's life and understood the life from both a private and public perspective.

This study used a synthesis of Denzin's (1989) interpretive biography and Dolby-Stahl's (1985, 1989) literary folkloristics as a framework for gathering, reading and interpreting the stories of the study participants (Williams & Holmes, 2005). Denzin's interpretive approach informed the gathering and reading of biographical data which

was analysed and interpreted using the literary folkloristic method. This strategy provided a contextualised narrative of the life experiences of high risk women who said no to RRS and is represented in Figure 5 below. While the research process has been kept intact, this has been presented here rather than at the beginning of the chapter as it represents how this approach was arrived at by the author as part of the process of using literary theory within the biographical method. Application of this approach is presented in the following chapter.

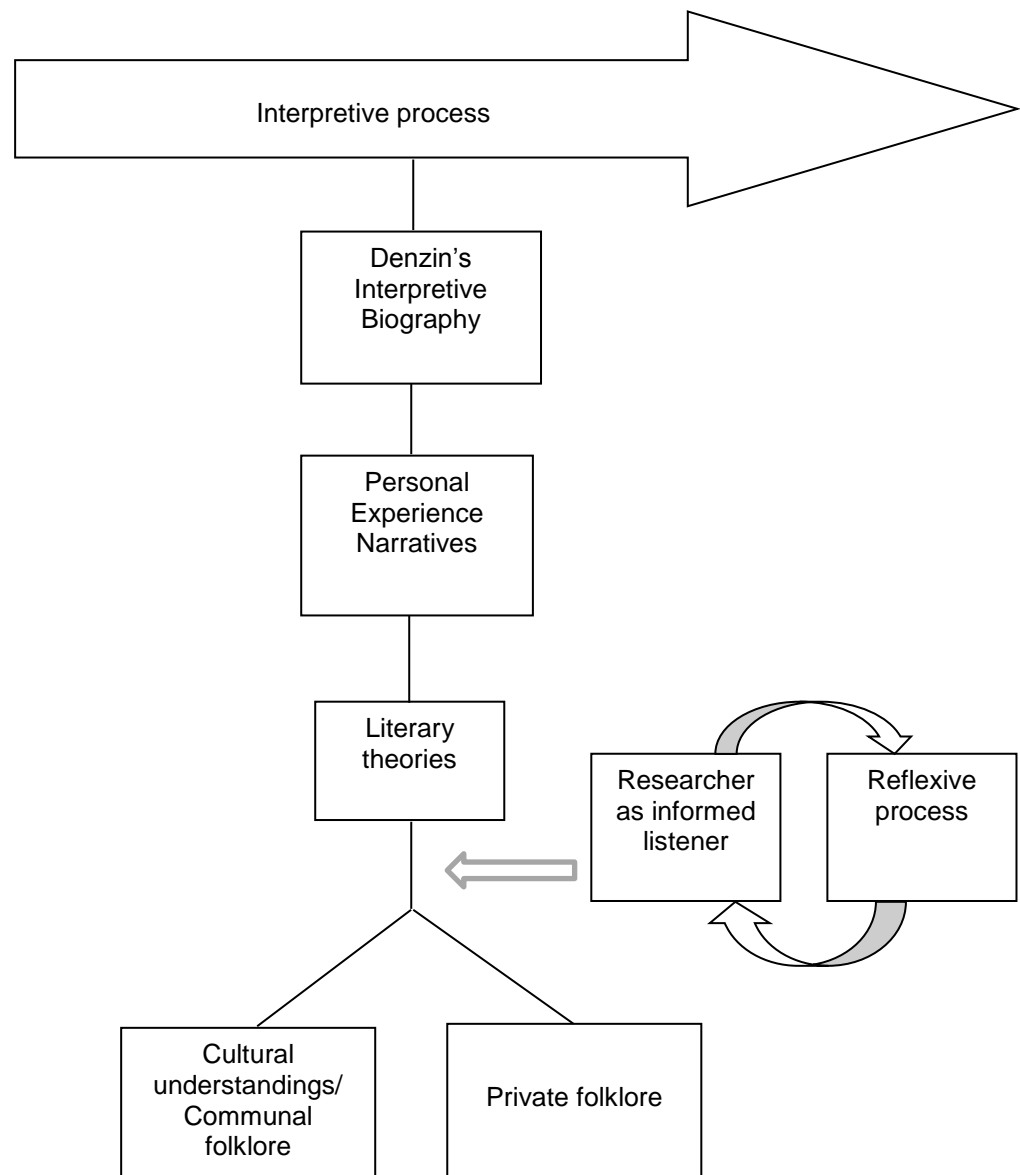


Figure 5: Overview of methodological approach taken in the study.

CHAPTER 4: THE METHOD

Introduction

In this study, Dolby-Stahl's (1985) literary folkloristic methodology was used within Denzin's (1989) interpretive biographical approach as a framework for the analysis of participants' personal experience narratives. Dolby-Stahl (1985) stops short of prescribing a particular method by which to undertake this process but does however offer guidance on prerequisites which researchers should attend to when utilising the literary folkloristic method:

(1) an acknowledged "documentary" frame; (2) clear allowance for the individual response of the listener; (3) commentary by an audience-interpreter whose relevant "folk group" is the same as the storyteller's; (4) identification of an audience-interpreter who knows the conventions of literary criticism...[]; (5) an audience interpreter willing to accept full responsibility for the act of interpretation. (Dolby-Stahl, 1985, p. 53)

From this, Hendricks (1999, p. 91) proposed an eight step process for conducting a literary folkloristic inquiry which was used to guide this study:

1. Locating the participants within a given social category
2. The identifying of salient themes and experiences in the participant's life.
3. The connecting of the subject's life history and life story to larger social meaning, including communal and private folklore.
4. Understanding that the subject's life story reflects a set of meaningful experiences which, when told create an emotional bond between the teller and the listener.
5. Realising that the private, inner meanings of these experiences to the subject can never be fully illuminated.
6. Interpreting the materials by sharing in the world of the experience of the subject.
7. Bringing the interpretive approaches of literary theory and criticism to bear on the life story materials.

8. Acknowledging that the researcher creates the document that is interpreted.

This provided a method which guided the study and through which the participants' stories could be gathered, read and interpreted.

Step 1: Locating the participants within a given social category.

Use of Dolby-Stahl's (1985, 1989) literary folkloristic methodology required study participants belong to an identified social group which shared an exclusive private folklore. This step therefore involved gaining access to BRCA1/2 mutation positive women who had said no to RRS.

Genetic testing identified the study participants as being at high risk of developing breast and/or ovarian cancer but they were asymptomatic, 'pre-disease' individuals who had chosen not to undergo RRS and were therefore not 'patients' in the traditional sense of the word. Although the number of women undergoing genetic testing for breast/ovarian cancer and having RRS continues to rise, the number of women who are offered then refuse RRS is not known. It may be women who say no to RRS are in effect rejecting medical intervention and may therefore be unwilling to continue medical observation and thus may be hard to reach participants.

Gaining access to participants

Women who had tested positive for a BRCA1/2 gene mutation but had said no to RRS were invited to participate in the study by placing advertisements (Appendix 1) in local newspapers in different regions of Scotland over a 12-month period. Initially this led to a sample of six women. A further two women were referred to the researcher by two of the initial participants who knew the other women to be high risk. One of these participants also lived in Scotland and one lived in the North of England. An initial telephone conversation was carried out with the potential participants to confirm

eligibility and willingness to take part in the study and arrange a mutually convenient place and time for interview to take place. Most interviews took place in the woman's home although two women requested to be interviewed elsewhere to avoid family members being aware of the interview: these interviews took place in a friend's house and a private room in a local library. A Patient Information Sheet (Appendix 2) was also posted at this point to allow the women to make an informed decision about participation.

In the end, six interviews were completed and used in the study as two potential participants withdrew at short notice. Qualitative research aims to collect data which is rich, meaningful and contextualised to create understanding rather than demonstrate statistical significance, making smaller sample sizes both sensible and practical (Morgan, 2008). This number of participants is appropriate when the aim of the research is to explore a shared perception, belief or experience amongst a relatively homogenous group (Guest, Bunce, & Johnson, 2006) and when analysis relies upon the in-depth interpretation of data from a small number of sources (Morgan, 2008) since larger samples may dilute the relative importance of each participant's responses (Lloyd et al., 2000).

Ethical considerations

Ethics in research became prominent following the abuse of human rights under the guise of research including Nazi experimentation and led to a number of ethical codes being formulated and adopted by those involved in research (Preissle, 2008). Although the purpose of research is to contribute to the existing body of knowledge on a given topic, the research process may result in the disclosure of information about individuals which is not already known (McHaffie, 2000), consequently the entire research process is subject to a number of ethical considerations from the choosing of

the research topic through to the dissemination of the findings (Bryman, 2004; Preissle, 2008).

Ethical issues raised by this study included the vulnerable nature of the participants, participants' autonomy, informed consent, potential harm to participants and issues of confidentiality and anonymity, all of which are interlinked.

Respect for autonomy

Autonomy is defined as "the ability of an individual to make reasoned decisions about issues which affect them" (Royal College of Nursing, 2009, p. 6) and can be threatened when research participants are vulnerable (National Health and Medical Research Council, 2007). The participants in this study could be considered vulnerable as they had been identified as having a BRCA1/2 mutation which predisposes to cancer but had said no to refused RRS. It was essential potential participants received adequate information to allow an informed decision on whether to participate to be made. Thus potential participants were provided with a Patient Information sheet (Appendix 2) which contained explicit information to protect patient autonomy namely:

- The aims and objectives of the study.
- Why their participation was being sought.
- Participation was entirely voluntary.
- The participants themselves would not directly benefit from the study.
- The participants could withdraw from the study at any time without prejudice.
- The study findings would be made available to others with an interest in the subject.

Informed consent

Informed consent is inextricably linked with autonomy (Beauchamp & Childress, 2013) and in addition to the measures outlined above, participants were given time to consider participation and have any outstanding concerns addressed prior to the interview commencing. Polit & Beck (2010) stated to respect participants' autonomy and ensure informed consent is obtained, the right to decline participation at any time and without prejudice should be apparent. Written consent was gained from participants (Appendix 3) confirming they understood the nature, purpose and possible consequences of taking part in the study and that they were free to withdraw at any time.

Potential harm to participants

The principles of beneficence and non-maleficence are applied in research to ensure the risks of research do not outweigh potential benefits (Duffy, 2008; Polit & Beck, 2010). Non-maleficence and beneficence are important concepts in the research process in part owing to the unpredictable element of discovery embedded in research (Orb, Eisenhauer & Wynaden, 2001). However, it could be argued it is impossible to eliminate all potential physical and emotional harm from the research process therefore the most important issue is the researcher strives to promote non-maleficence and beneficence.

There was no potential for physical harm in this study although it was possible emotional upset or distress could occur as a result of discussing sensitive issues in the interviews. Participants were provided with contact numbers for reputable support services (Appendix 4) in order they could access support were it required. It was also possible a participant could have, in the course of telling their story, reconsidered the decision to refuse RRS. Although none articulated such a desire, the

researcher clarified participants were aware they could contact their General Practitioner or Genetics Clinic for further discussion if necessary.

Confidentiality/Anonymity

All research participants have the right to privacy (Duffy, 2008; Polit & Beck, 2010) and the concepts of confidentiality and anonymity are used to safeguard privacy. To ensure confidentiality, participants' identities and the information they provided will not be displayed publicly without prior consent. The patient information sheet made participants aware the study findings may be presented at conferences and/or published but all information provided would be anonymised. Anonymity is the process of separating data from provider, and may be full or partial (Ogden, 2008). Full anonymity occurs when no-one (including the researcher and the participants) can identify who provided the data. In this study, partial anonymity was achieved by using pseudonyms on the interview transcripts so only the researcher was able to link data with participant (Ogden, 2008). Furthermore, data obtained was edited to ensure the participant was not identifiable from other means such as age, occupation or distinguishing features (Redsell & Cheater, 2001).

In accordance with the National Health and Medical Research Council guidelines on Ethical Conduct in Human Research (NHMRC, 2007), electronic data was stored on a password protected computer and hard copies of data stored in a locked cabinet. Participants' details were kept separate from their responses at all times by use of identification codes and the data collected was enough to answer the research questions but not excessive. The data will be held until the study is completed and published then destroyed in accordance with the NHMRC (2007) guidelines and Edith Cowan University policy.

Gaining Ethics approval

Ethics approval was obtained from the Edith Cowan University Ethics Committee and the researcher was required to submit an annual report to maintain the currency of ethics approval.

Inclusion criteria

- Identified genetic predisposition to developing breast/ovarian cancer.
- Offered and declined RRS more than six months prior to recruitment.
- English speaking Western Caucasian women.
- Age > 18 years.

Exclusion criteria

- Significant co-morbidity which may shorten life outside potential cancer diagnosis.

Justification for inclusion/exclusion criteria

The inclusion criteria were necessary to ensure participants were able to provide the data required for the study. A period of at least six months between saying no to RRS and study recruitment ensured participants had time to live with the decision. Non-western, non-Caucasian women were excluded to avoid cultural influences which may impact on decision making, body image and health beliefs and whilst important, were not the focus of this study. Women who had significant co-morbidity and/or a potentially life-limiting illness may have attitudes and beliefs which influence health behaviours which are not the focus of this study.

Step 2: The identifying of salient themes and experiences in the participant's life.

This step involved the gathering and recording of the participants' stories of being identified as high risk of developing breast/ovarian cancer and saying no to RRS. Denzin's (1989) interpretive biographical method contends biographical texts begin with a family history and collate a chronological sequence of experiences and events in relation to turning point or epiphany moments in the individual's life. These turning point moments equate with what Dolby-Stahl (1989) referred to as themes or ideas within the text and are a means through which the teller of the story reveals personal values and character traits.

Dolby-Stahl (1989) posited themes which emerge from personal experience narratives often represent items of folklore and cultural norms. In this way, the salient themes reflect societal expectations which influence how a person experiences life and tells their story (Williams & Holmes, 2005). In this study, the participants drew from communal and personal folklore to try to make sense of their experiences. For example, beliefs about what a woman should look like often conflicted with beliefs about how women, especially mothers, should respond to the threat of cancer.

The participants were asked to tell their story, recounting events and experiences relating to realising there might be a history of breast/ovarian cancer in the family, being identified as having a genetic predisposition to developing breast/ovarian cancer and saying no to RRS. This required the participants to re-live and re-interpret certain experiences (Denzin, 1989) and revealed themes and turning point moments related to the meanings women attributed to those experiences and attempts to make sense of them.

Data collection process

Semi-structured interviews were used to gather biographical data for analysis and interpretation. This was an appropriate method of data collection as it provided a focus in terms of the data to be collected but allowed flexibility in terms of the wording and sequencing of questions, and clarification of participant responses at the time of interview (Parahoo, 2006). An interview guide (Appendix 5) which contained open-ended questions pertinent to the areas of interest (Bryman, 2004; Polit & Beck, 2010) was developed which allowed the researcher to capture the world through the eyes of the participants. The interview guide was carefully constructed to gather data which would address the study aims whilst avoiding leading and/or ambiguous questions and jargon (Bryman, 2004). The questions whilst open-ended also ensured the participants remained focussed on the aims of the study (Polit & Beck, 2010). The final question allowed participants the opportunity to add anything important not already covered (Bryman, 2004). The interviews were tape-recorded for later transcription with participant permission.

In keeping with the methodological approach underpinning this study, it was important the participants were able to tell their story freely to an interested listener to ensure the story told reflected what was important to them and what sense was made of the experience at the time. However, it was also important the data collected was able to address the study aims. Consequently the interview guide was used only when the participants required prompting and to keep the focus on the experiences related to the study aims. The interviews varied in length from approximately 55 minutes to 90 minutes.

Field notes

Field notes are a record of concomitant observations collected by the researcher during the conduct of qualitative research (Thorpe, 2008), and facilitate a deeper

understanding of the phenomenon under study (Polit & Beck, 2013). Field notes contribute to the construction of an account of personal meanings of experience which can be reflected upon at various points during the research study.

In this study, preliminary field notes were completed immediately following the interview to avoid disturbing the participant or obstructing the flow (Holloway & Wheeler 2010; Polit & Beck, 2013). These were added to when the audio-recordings of the interviews were listened to and again when the transcripts were read. The field notes included commentary on but not limited to, the creation of intimacy, the participant's demeanour and mannerisms, initial thoughts, feelings and assumptions, participants' non-verbal communications, any surprising findings/feelings and personal reflections of the researcher. In keeping with Denzin (1989) and Dolby-Stahl (1985), they also included reference to what emerged as turning point moments for each participant.

The field notes were useful in contextualising the participants' experiences and for collecting evidence of what was not said in their stories. For example, the participants' were generally reticent about discussing the mastectomised bodies of other women in a negative way, but their body language and non-verbal communications suggested they held negative views about this. One participant for example, when discussing her sister's mastectomy, did not say how she would look if she lost her breasts but rather said; "I would think I looked [pause] you know?" whilst making a squeamish face.

Data analysis

Following collection and transcribing of the interview data, the participants' stories were analysed for significant events, ideas in the text, themes and categories of most concern to the teller and researcher (Dolby-Stahl, 1985). The resulting personal

experiences narratives were created by linking non-random events in relation to the participants' experiences in a meaningful way (Denzin, 1989). The first significant cancer death in the family or realisation there might be a family history of cancer in the family marked the beginning of the personal experience narrative. Since the presence of a gene fault which predisposes a woman to developing cancer is a permanent biological marker, the life trajectory of the participants in relation to turning point or epiphany moments up to completion of interviews provided the scope of the personal experience narratives.

Key steps in narrative analysis (Blix et al., 2012; Fraser, 2004; Liamputtong, 2009; Riessman, 2008) were then applied within the framework of Denzin's (1989) interpretive biographical method as follows. Following transcription, the audio recordings of the participants' personal experience narratives were listened to so the stories were heard and the emotions of the participants experienced. Simultaneously, the transcribed texts were read to immerse the researcher in the data. Field notes were consulted and a reflexive journal maintained to describe feelings and emerging thoughts and considerations. The transcripts were then read again carefully line by line and points of interest, importance and significance highlighted on the transcripts. The researcher worked with one personal experience narrative at a time, isolating and ordering relevant episodes into a chronological biographical account. Attention was paid to the types and directions of the personal experience narratives and any conflict and contradictions present. Individual personal experience narratives were analysed for themes, ideas, epiphany moments, underlying assumptions, what was emphasised, what was glossed over, pauses, gaps and silences and what these suggested. The overall focus was on illuminating patterns of meaning and experience. Following this, a process of interpretation took place to make sense of the participants' experiences by illuminating larger cultural contexts and ideological forces which shaped experience (Denzin, 1989). Dolby-Stahl's (1985) literary

folkloristic methodology was applied using the techniques of Foucauldian, Marxist and Feminist literary criticism. This process is discussed in Step 7.

Step 3: The connecting of the subject's life history and life story to larger social meaning, including communal and private folklore.

In this study, the participants told stories about their experiences of being identified as having a BRCA1/2 mutation then being offered and saying no to RRS. However, a personal experience narrative is not an independent production: the woman's story is emitted outward when told but is taken inward into a social group where it acquires structure, meaning and context (Denzin, 1989).

Barnett (1998, p. 194) described personal experience narratives as "embedded texts that connect the social and the private". This compares with Dolby-Stahl's (1985, 1989) concepts of communal and private folklore. Communal folklore is that which is shared in the social world while private folklore is that which is exclusively generated by a particular group, in this case, the high risk women who said no to RRS. Communal folklore is identified within texts as representations of traditional ideas which symbolise ideas, values and themes which are widely held in the cultural/societal group and thus allow creation of a social reality (Dolby-Stahl, 1985). Communal folklore serves as a form of "collective memory" (Trubshaw, 2002, p. 43) which delineates how people function in society and how women should look and act. However, high risk women who say no to RRS may develop private folklore as a result of their shared experiences. Private folklore concerns deeply personal and idiosyncratic values and ideas which create meaning in a text but are usually excluded from communal folklore (Dolby-Stahl, 1985). Thus searching for private folklore embedded in the participants' stories facilitates the creation of meaning of the inner life of the teller. Inherent in this is acknowledgement the participants' experiences although personal, occurred within Western society and must, therefore, be

interpreted in light of social structures and ideologies which shape and influence how a life is lived and experienced (Denzin, 1989).

Women are social beings who translate signs into meaning to make sense of the world. Personal stories and those inherited from others are brought to bear on experience to create order and make sense of experience (Denzin, 1989; Frank, 1995; Rosenbaum & Roos, 2000). The participants in this study created their own stories but also inherited stories from others in society in relation to the breasts, ovaries, cancer and surrounding folklore. On the one hand, the breasts and ovaries symbolise femininity and womanhood and Western society expects women possess these organs (Ehlers & Krupar, 2012). Simultaneously, Western discourse demands women keep themselves healthy, nurture the family and generally conform to what is expected of the female role (Acero, 2012; Gibbon, 2006). This study argued that these conforming standards included being compliant with Western medical discourse which constructed RRS as a utilitarian option for staying healthy. To understand the decision to say no to RRS, one must understand the wider societal discourses and communal folklore which permeate Western society.

Personal experience narratives then are created from stories which are both learned and told in cultural and social groups (Denzin, 1989) reflective of the discourses and power relations of the time (Riessman, 2008). The participants' experiences of their disruptive life events and the telling of them are contextually bound to social, cultural and historical milieus. To understand the life of the woman and the experiences contained within it, one must seek to understand these larger structures which impact upon how a life is lived and experienced (Denzin, 1989). In this study, this step involved connecting biographies and lived experiences including epiphanies, to the groups, conventions and social, cultural and historical relationships which surround and shape people's lives (Surr, 2006). Accordingly, the participants' personal

experience narratives and the epiphanies contained within them were contextualised against a backdrop of social, gender and medical discourses which define what women look like, how women behave and how women respond to the threat of cancer. Linking the participants' stories to wider social meanings involved consideration of how dominant discourses and social conventions shaped the interpretive framework for understanding the personal experience narrative (Fraser, 2004). Their personal experience narratives were cultural productions which mirrored and reflected characteristics, values and beliefs which are shared in the society which produced them (Lewis, 2010). Dundes (1980) advocates such cultural productions are lore and should be contextualised within the social and cultural constructs of the folk who produce them and their shared cultural background.

Dolby-Stahl (1989) proposed eight key folk groups which shape a storyteller's life and provide understanding of their social world: family, ethnic, religion, place, age, sex, social network and occupation. Of particular relevance to this study, these folk groups typically generate and maintain folklore in relation to gender, heritage, familial ties, relationships and kinship. Communal folklore equates having two breasts and ovaries with femininity and womanhood and constructs women as self-sacrificing, nurturing individuals who put the needs of the family first (Acero, 2012). Simultaneously, cancer folklore conveys everyone to be at risk of cancer and a taken-for-granted assumption medicine is the assumed solution to cancer (Clarke & Everest, 2006). This communal folklore is reinforced by the medicalisation of women's bodies which positions the doctor as expert over women and suggests sensible women do whatever it takes to stay healthy for the sake of the family. In this study, it was argued larger societal meanings acquired through discourse, ideology and communal folklore transmitted conflicting messages to women at high risk of developing breast/ovarian cancer. This highlighted the conflict and contradiction which may exist between cultural/societal and personal realities therefore it was not surprising high risk

women who said no to RRS developed a private folklore to make sense of their experiences and explain their behaviours.

In summary, in order to understand the decision to say no to RRS, it was necessary to understand the experiences of the participants which led them to the decision to refuse surgery, and to contextualise these socially, culturally and historically. Allowing the participants to tell their stories illuminated the reality of these women's lives and exposed the disunity between societal expectations and real life experiences and between communal and private folklore.

Step 4: Understanding that the subject's life story reflects a set of meaningful experiences which, when told create an emotional bond between the teller and the listener.

A central assumption of Dolby-Stahl's (1989, 1985) methodological approach is personal experience narratives are replete with private folklore and express aspects of the inner life of the storyteller. The revelation of private folklore was a crucial step in understanding the experiences which led to the decision to say no to RRS. Dolby-Stahl (1985) further contended since private folklore is selectively rather than widely shared, it will only be revealed during the research process when intimacy is present between the teller and the researcher-as-listener. The creation of intimacy is thus a pre-requisite for uncovering meaningful experiences, epiphanies and private folklore.

For Dolby-Stahl (1985), intimacy is the creation of an emotional bond between two people who are considered to be of equal status and is essential if authentic interpretations of the text are to occur. Intimacy develops between the participant and the researcher-as-listener because there exists a shared body of knowledge and realisation the experience is mutually understood (Williams & Holmes, 2005). Moreover, the creation of intimacy guarantees the value and importance of the

participants' responses and avoids the participant feeling devalued in the research process (Williams & Holmes, 2005). This is particularly relevant in studies where participants struggle to have their voice heard because their actions are at odds with dominant discourses and communal folklore, such as the participants in this study.

The creation of intimacy was an explicit aim in this study and the researcher took steps to facilitate emotional bonding with the participants prior to and during the interviews. Participants initially responded to an advertisement placed in local newspapers which was carefully worded to reach out to women using plain language and requested an initial telephone contact from the women to a named researcher (the Principal Investigator). A separate mobile phone was used for this purpose and the researcher took care during the initial contact to sound friendly and gently outline the study aims. A balance was struck between creating intimacy and ensuring the participants gave consent freely. The researcher explained her interest in the study and what she aimed to achieve by collecting the participants' stories.

The interviews were arranged at a mutually convenient time and place, mostly in the participants' homes. Those who requested to be interviewed out-with the home were easily accommodated by arranging a quiet, private room in a local library or interviewing in a friend's home. The researcher was mindful to make this process as straightforward as possible to build a bond with the participants and facilitate the creation of intimacy. It was also necessary to ensure the participants knew that the experience was mutually understood as intimacy develops when the researcher shares aspects of the teller's folk group (Dolby-Stahl, 1985). This was achieved through a short explanation of the researcher's interest in their stories and through an exchange of information about shared aspects of life such as children, employment and general life experiences.

Dolby-Stahl (1985) also argued that people who choose to tell their stories to an interested listener seek the creation of intimacy as a way of sharing private folklore. The creation of intimacy was therefore an aim of both the teller and the researcher. It is precisely this desire for intimacy which motivated the participants to engage in the storytelling process in order that private folklore and personal meaning were unveiled: “without apology, the personal narrative makes a gesture toward intimacy” (Dolby-Stahl, 1985, p. 48).

It was apparent the participants in this study were eager to tell their stories and grateful for the opportunity to be listened to. This suggested that the participants enjoyed the experience of intimacy through telling their story to an interested listener who did not judge them or attempt to persuade them otherwise. All participants commented they had, at times, felt unable to discuss their experiences with people close to them for fear of causing distress or being misunderstood.

In summary, the creation of intimacy and the telling of the story to the researcher-as-listener drew the researcher into the teller’s world and allowed illumination of epiphanies and turning point moments which shaped the teller’s life and contributed to the story told. Focussing on the researcher’s desire to tell the participants’ stories and to shape understanding of their experiences, meant the participants felt listened to without being judged and all expressed gratitude at being able to tell their story to an interested listener.

Step 5: Realising that the private, inner meanings of these experiences to the subject can never be fully illuminated.

Utilising literary folkloristic methodology requires the listener to enter the world of the teller and perceive the world through the teller’s perspective (Hendricks, 1999; Williams & Holmes, 2005). The creation of intimacy (Dolby-Stahl, 1985) draws the

researcher-as-listener into an intersubjective agreement with the participant-as-teller as to how the participant's experience was. The stories told covered a section of each participant's life including epiphany moments in their life trajectory, which were offered as legitimate accounts of experience. The participants were recognised as experts of their own experiences (Grassley & Nelms, 2009); however, the role of the audience/listener in applying their own interpretation to what was said and heard was equally acknowledged (Gray, 2007). Thus personal, social, cultural and historical influences on both teller and listener shape the story told and heard, making the entire process an interactive and creative act (Dolby-Stahl, 1989) open to multiple interpretations (Denzin, 1989).

In this study, the participants were asked to tell their stories for a purpose: to address the research aims, allow the researcher to make-meaning of their experiences and communicate this meaning to a wider audience. The participants' personal experience narratives were literary productions because the story-teller continually deliberates on what to say and what to keep silent (Dolby-Stahl, 1985) depending on the cultural and societal conventions of the time (Denzin, 1989; Thorne et al., 2004). Moreover, the participants in this study communicated their stories through language from which literary texts, in the form of personal experience narratives, were created.

Integral to this study then is how the teller uses language to tell the story and how the language/story is interpreted by another (Bornat, 2008; Williams & Holmes, 2005), in this case, the researcher. Language is recognised as a socially constructed medium which creates rather than describes reality (Haralambos & Holborn, 2000) and which acquires meaning through time and context bound social practices (Sandberg, 2005). Thus language is not abstract but rather confers meaning within particular discourses. The unstable, ambiguous and changing nature of language mean a number of

differing interpretations of what reality is potentially exist (Denzin, 1989; Haralambos & Holborn, 2000). This in turn means a straightforward representation of reality is unachievable as the 'truth' of any story is dependent upon future readers' interpretations of it (Frank, 1995; Gray, 2007). In keeping with Denzin (1989), the researcher's aim was to present a credible interpretation of the personal experience narrative, one which demonstrated verisimilitude, whilst acknowledging it is one of many which could have occurred.

The approach in this study held that the literary texts produced by the participants were reflective of personal, social, cultural and historical influences on the life lived and contained reference to communal and personal folklore. Their stories were interpreted through the use of language and by the researcher actively drawing out meaning and understanding not necessarily articulated in the texts (Bornat, 2008). The telling of the story to an informed listener (Dolby-Stahl, 1985) was a joint enterprise which utilised shared interpretive practices (Bornat, 2008). However, although the participants were exposed to communal folklore and shared aspects of private folklore, each participant's story was different; therefore an overall depiction of one universal reality was not possible (Gray, 2007). Additionally, the act of telling a story to a listener requires the teller to re-live and re-interpret the experience in response to their own and others' reactions to it (Denzin, 1989). Rich (1972, p. 18) referred to this process as "re-vision": a process whereby storytellers look back at experience through fresh eyes as new insights into experience are gained through revisiting the story. Consequently, the inner experiences of the study participants can never be fully illuminated as there are multiple un-ending numbers of possible stories which could have been told. Moreover, the subjective nature of language and plurality of the text means there can be no final or fixed meaning located in the participants' stories. This was acknowledged by Denzin (1989) and Dolby-Stahl (1985) who conceded it is not possible to become the person telling the story therefore it is not

possible to know everything the teller knows: the most the researcher can do is present a credible interpretation of the participants' experiences whilst accepting other interpretations of experience and the meanings attached to them were possible and may yet occur in the future.

Step 6: Interpreting the materials by sharing in the world of the experience of the subject.

Dolby-Stahl (1985) described an informed listener as one who shares aspects of the participants' folk group and takes steps to become as fully informed about the phenomenon under investigation as possible. Likewise, Denzin (2001, p. 67) used the term "informed reader" to describe someone who knows the language used in the participant's story; knows at least partially the biography of the teller; is able to take the teller's perspective and shares some of the experiences of the teller. The informed reader also accepts meaning is created through the response to the story and takes steps to secure an interpretation which is faithful to the storyteller's perspective.

In this study, the researcher was motivated by a genuine desire to enter into the worlds of the participants, to create understanding of their experiences and to make meaning of the decision to say no to RRS. The researcher is a woman in Western society and as such, shared aspects of the participants' folk group and was exposed to the same dominant discourses and ideological influences which impact on how a life is lived and experienced. Through the creation of intimacy and immersion in the participants' stories, the researcher was able to come to know the biographies of the tellers and take the participants' perspectives in the stories told. The researcher was well informed about the phenomena under investigation through completion of a comprehensive literature review on topics relevant to the study. The researcher also drew upon prior experience working with women having genetic counselling for HBOC

and both affected women and high risk women undergoing breast/ovarian surgery. This provided prior understandings which were incorporated into the interpretation of the participants' experiences to create new understanding (Denzin, 2001). Finally, the researcher acknowledged the interpretation provided is one of many possible interpretations which could have been made of the participants' experiences.

Step 7: Bringing the interpretive approaches of literary theory and criticism to bear on the life story materials.

Dolby-Stahl (1989) argued personal experience narratives were literary works since a single truth cannot be presented; rather the listener actively interprets the story being told in a literary process. Moreover, whilst anyone can listen to a narrative or story and offer an account of what they believe it to mean, an informed listener (Dolby-Stahl, 1985) is able to interpret the story in such a way as to make it collectively meaningful through the application of the techniques of literary interpretation and critique (Denzin, 1989). An informed listener uses literary theory to deconstruct stories of experience and offer an interpretation in light of social, cultural and historical influences thereby demonstrating *how* their particular interpretation came about (Dolby-Stahl, 1985). Such literary techniques, therefore, capture the spoken word as text which may be later analysed and interpreted to create understanding of certain life experiences, or as Dolby-Stahl (1985) suggested, provide a means by which the teller can teach the listener to know her/him better.

Integral to this is the connection of biographically meaningful experiences to the society in which the participants lived and to larger social, cultural and historical structures which influence how a life is lived and experienced (Denzin, 1989). The literary nature of personal experience narratives and the resolve to uncover folklore involves the use of an interpretive framework based on various literary theories, an approach which enables the researcher to make sense of the personal experience

narratives in light of both communal and personal folklore (Williams & Holmes, 2005). In this study, Foucauldian, Marxist and Feminist literary theories informed the analysis and interpretation of the personal experience narratives and allowed an interpretation which was both culturally and personally grounded (Hendricks, 1999). The following section describes and justifies the application of these literary theories in this study.

Overview of Literary Theory

Literary theory is defined as “the systematic account of the nature of literature and the methods for analysing it” (Culler, 2011, p. 1). Literary theory informs literary criticism which Newton (1990) contended is concerned with interpretation, highlighting distinction must be drawn between reading written works and understanding and interpreting same works. Literary theory can be understood as a tool used in the practical reading of the text (Brewton, 2005) to understand the many different ways of interpreting text (Eagleton, 1999). Contemporary literary theory creates a relationship between the author, the literary work and the reader and allows examination of the ways in which race, gender, class and so forth are represented in literature and may influence the author’s perspective (Brewton, 2005). Literary theory therefore provides a lens for the study of literature and also for the analysis of cultural, historical and social influences which both create the text and influence how it is interpreted.

Various schools of literary theory exist, each with a set of assumptions or theoretical positions which allow critics to offer an interpretation of the text in relation to aspects or characteristics of the work considered most important (Culler, 2011). Culler (2011) cautioned against treating these schools as competing approaches because they share similarities as well as differences: all focus on how the reader responds to the text. Thus literary theory is most useful when it is used to problematise social and

cultural assumptions as this allows an exploration of how meaning is created (Bertens 2008; Culler, 2011).

The birth of modern literary theory is attributed to the nineteenth century German philosopher Friedrich Nietzsche's critique of knowledge and his theory facts only existed after they had been interpreted (Brewton, 2005). Nietzsche's (1873) influential essay "On Truth and Lies in an Extra-moral Sense" presented a persuasive thesis on language and literature, and contended no text speaks for itself: meaning is only acquired through an interpreting reader. More recently, the 1930s School of Formalism took a structuralist approach which was concerned with literary form and focussed on the structures of language rather than thoughts, feelings or subject matter within the literary text (Eagleton, 1996). The Formalist approach was criticised on the basis literary devices found in the 'special' language of literature were also found in everyday language, and it failed to consider the context in which the language/literary work was produced (Eagleton, 1996). This criticism came to be seen as a serious flaw as the world changed socio-economically and politically and poststructuralist critical approaches which focussed on social, cultural and political contexts took centre stage (Bertens, 2008; Eagleton, 1996).

Poststructuralist approaches consider literature in light of social, cultural and ideological influences on what was written and how it could be interpreted (Eagleton, 1996). Language is considered as process rather than structure as it is the means through which literary productions are communicated. Language is purposeful: it is constructed and employed for a reason hence rather than representing reality, language effectively creates reality because what is said and heard acquires meaning through language and the social conditions in which it is defined and used (Holcombe, 2007; Sandberg, 2005). Hence there can be no single truthful interpretation of an

experience: interpretation was temporary and only applicable to the discourse in which it was produced (Denzin, 1989; Dolby-Stahl, 1985).

In keeping with Denzin's (1987) and Dolby-Stahl's (1985) methodological approach, application of poststructuralist literary theory was therefore appropriate in this study. The participants in this study communicated their stories of experience through language which was then converted into a literary text. They told a story, one of many which could have been told: an edited version of reality which shared what was important to the participants' and how they made sense of experience at the time. The participants' stories and the meanings attached were acknowledged as temporal, plural and open to multiple interpretations. This was of great importance, as one can never accurately replicate a life or life experience; therefore, the focus was on the text created by the individual and not the individual per se (Denzin, 1989). Therefore, participant's personal experience narratives were analysed for specific purposes and enabled a focus on meaning in the text from which an understanding of their private folklore was created. The following sections discuss and justify the literary theories utilised in this study namely Marxist, Foucauldian and Feminist literary theory.

Marxist Literary Theory

Introduction

Marxist literary theory is a form of critical inquiry which interrogates all societies and their texts in relation to shared attitudes within a culture and specific issues including class, gender and race (Bertens, 2008). It contends subconscious drivers determine how individuals perceive and situate themselves within society: "it is not the consciousness of men that determines their existence, but their social existence that determines their consciousness" (Marx 1859, cited in Bertens, 2008, p. 63). In other words, an individual's social circumstances determine his or her life. This in itself is not controversial: for example, a relationship exists between poverty/wealth and the

development of certain diseases, or life opportunities. However, Marxists are sceptical of the belief individuals could alter personal life circumstances through education, employment or such, arguing instead capitalist society is structured in a way to maintain power in the hands of the ruling classes.

Marx postulated society's base determined its superstructure (Bertens, 2008): economics is the base upon which the superstructure of social, political and ideological realities are built. Education, the Arts including literature, culture, religion, institutions such as medicine and the legal system and values and beliefs are contained within the superstructure and as such are primarily influenced by economic drivers (Bertens, 2008). Marxist literary theory contends the way in which society is organised drives the production of literary texts: literature is a production of capitalist society not a reflection of it (Tyson, 2015). Literary texts are analysed for themes which illuminate 'hidden' messages which identify and maintain the position of the ruling classes.

The methodological approach taken in this study presupposed living occurs within a construct, therefore to understand the participants' decisions to say no to RRS, one must understand the social, cultural and historical milieus which led to that decision. Since Western society is a capitalist society in which ideology shapes human experience (Denzin, 1990), Marxist literary theory provided a useful means of examining the participants' stories for themes in relation to beliefs about gender, sexuality, the family and other social and cultural influences relevant to the study. Several key areas of Marxist thought are particularly relevant to this study and a summary of these now follows.

Ideology

The concept of ideology and its importance in organising and controlling human behaviour is central to Marxist literary theory. In its broadest sense, ideology is a belief system (Tyson, 2015). Eagleton (1996, p. 13) defined ideology as a “concealed structure of values which informs and underlies our factual statements” and explained ideology encompasses an individual’s unconscious images of themselves and others. Marx argued ideology created a “false consciousness” (Bennett & Royle, 1999, p. 161), a false representation of society, for example, that disease is caused primarily by lifestyle choices as opposed to economic and social deprivation. This false consciousness existed subliminally and persuaded individuals of the rightfulness of the class/capitalist system, directed people in how they should live their lives and prevented recognition of the true society which repressed them (Bennett & Royle, 1999; Tyson, 2015).

The French Marxist Louis Althusser (1918 – 1990) expanded Marx’s concept of ideology to include a critique of the ways in which systems and structures in society maintained and reproduced ideologies. Sawyer (2002) views Althusser’s concept of ideology as an extension of Gramsci’s (1971) original notion of hegemony. That is the State exerted power over its inhabitants through both coercive and subtle means of control: ideology is a form of invisible power which acts as a social regulator. Althusser (1971) used the term ‘ideological State apparatuses’ to describe key agencies involved in maintaining ideological control of the population including the Church, the media, political parties, the family, schools, medicine and cultural agencies such as the Arts, literature and those associated with sport. Distinction was drawn between repressive State apparatuses which sat in the public domain and included the police, penal system and the army, and ideological State apparatuses which sat in the private domain, such as those identified above. Althusser (1971) further argued although separate entities, repressive and ideological State

apparatuses were interlinked and neither entirely excluded the other: although medicine is a form of ideological control, it has certain rules which can exclude and curtail, for example being removed from a General Practitioner's patient list or being denied a particular treatment if certain symptoms cannot be proven to exist.

The most successful ideologies are those which appear natural or given (Bennett & Royle, 1999; Tyson, 2015) which perpetuates their legitimacy and influence (Kroska, 2007). For example, gender ideologies serve as unconscious drivers for taken-for-granted beliefs about male and female behaviours in relation to the family (Davis & Greenstein, 2009), including the woman's role as carer, nurturer and homemaker (Acero, 2012; Kroska, 2007; Mikkola, 2012; Warner & Procaccino, 2004) and responsibility for the health of families Acero, 2012; Ferguson & Kasper, 2000). The natural authenticity of ideology validates individuals as free, that is outside ideology, when in reality they are within ideology. Thus ideology effectively denies its own existence. Althusser (1971, p. 175) explains this paradox thus:

That is why those who are in ideology believe themselves by definition outside ideology: one of the effects of ideology is the practical *denegation* [original emphasis] of the ideological character of ideology by ideology: ideology never says, "I am ideological".

Althusserian theorising of ideology has been criticised for suggesting ideology was oppressive to the point of subjugation (Eagleton, 1976) thus leaving little room for ideological struggle. However, it could equally be argued that Althusser's theory does allow for ideological struggle to be analysed since it contends all humans are inherently ideological (Bennett & Royle, 1999) and thus define themselves as individuals through ideology. Herein lies the crux of Althusser's argument: individuals create personal ideologies whilst ideology simultaneously creates individuals as subjects. Hence, ideology is both an internal and an external driving force leaving scope for individuals to create personal ideologies which challenge or resist the dominant externally driven ideological forces.

To sum up, the concept of ideology is central to Marxist literary interpretation and critique. Ideology functions as a means of social control because what appears natural or given is intended to maintain the power of the ruling classes in capitalist society. A Marxist critique is therefore concerned with the ideological function of literary texts and seeks to reveal underlying social and political significances concealed within the text which perpetuate the reproduction of social power. The following section explores the ideological function of literature in more depth.

Literature as an ideological tool

A Marxist critique contends literature is a product of socioeconomic and ideological conditions rather than a reflection of such, since authors are humans and humans are products of ideological and cultural conditions (Tyson, 2015). Tyson (2015) further argued the critique of literature can encourage a robust examination of historical and material conditions and ideologies hence literature is inextricably linked to historical, social and cultural practices which influence both its production and how it is read.

From this, an understanding of literature as an ideological tool in Western society is achieved. Literature produces and is produced by ideology (Bennett & Royle, 1999), reflects “the ideology from which it is born” (Althusser, 1971, p. 222) and functions to allow individuals to see what the ruling classes allow to be seen (Eagleton, 1996). Eagleton (1996) further contended literature became an agent for the reproduction of ideology when religion began to lose its pacifying influence on the working classes in Victorian times. Religious ideology demanded individuals lived a meek life, conformed to social norms, were self-sacrificing and generally worked hard to achieve an ‘honest’ living which created the “social cement” (Eagleton, 1996, p. 20) in society. However, as religion began to lose appeal and the working classes began to demand more, ‘English literature’ emerged as an academic subject through which desirable morals, values and behaviours were promoted which allowed individuals to

understand what a 'good citizen' was and how one should act in society. Qualities such as generosity, patriotism, heroism and tolerance were identified as timeless truths which individuals should seek to exhibit, thus distracting the working classes from socio-economic issues such as low wages, poor housing and working conditions and ill-health (Eagleton, 1996). Literary texts were therefore considered as sites of ideology production and reproduction. The text was not a passive reflection of ideology but rather a site of conflict and difference, where values, prejudices, beliefs, knowledge and social structures were produced and transformed (Bennett & Royle, 1999).

Macherey (1978) further proposed literary works were tied to ideology as much by what they did *not* say as by what they did. The presence of ideology is also felt in the significant silences, gaps and absences in a text because some things are "ideologically forbidden" (Eagleton, 1976, p. 32) thus unable to be said. These gaps are unintentionally omitted from the author's text and imply the text is always incomplete, because there is always something else which could have been said, had it not been silenced by ideology (Eagleton, 1976). A Marxist critique aims to make the silences speak and reveal the unconscious content which resides behind the expressed text to expose the conflict between the spoken and unspoken text and the text's relationship to ideology (Abrams & Harpham, 2009). Thus, understanding of a text requires the reader to consider both what is present and what is not; the unsaid, the glossed over and the ignored, and to link these to social, cultural and historical influences on the production of the text. Accordingly, examining gaps in the participants' personal experience narratives exposed what women may have felt unable to say because it conflicted with ideology. It may be postulated that the participants' narratives revealed gaps and significant silences which may represent resistance to the prevailing dominant ideologies and which were reflective of individual ideology and private folklore.

Medicine and ideology

A Marxist critique of Western medicine identifies medicine as an ideological tool which mirrors society's class structure and maintains patterns of domination (Waitzkin, 1984, 1989). Waitzkin (1984, 1989) contended Western medicine's authority to determine who was fit to work exposed medicine as an institution of social control and medical encounters as sites for the transmission of ideological messages. Waitzkin's (1984) seminal research examined transcripts of medical encounters and found the doctor-patient interaction contained ideological themes and messages which reinforced existing patterns of domination and relations of economic production.

Of particular note, Waitzkin (1984) found a key way in which medical social control occurred was through support for the institution of the family. From a Marxist perspective, the relationship between the family and successful economic production in capitalist societies is paramount. The role of the female in both economic production and sexual reproduction places women central to the maintenance of a healthy productive workforce. Women function as the 'gatekeepers for health' (Acero, 2012; Warner & Procaccino, 2004) and take primary responsibility for the family's health (Davis & Greenstein, 2009; Lerner, 2000). Patterns of sexuality, child rearing and stereotypical roles including the female as mother, homemaker and nurturer, sustain the population's acquiescence and participation in economic production (Waitzkin, 1984, 1989). Women who disregard health messages in relation to breast/ovarian cancer development are therefore putting not only themselves, but also the institution of the family at risk.

Ideological messages communicated through doctor-patient interactions are endorsed by other ideological state apparatuses including the education system and the media and legitimised by the symbolic impact of medical science (Waitzkin, 1984). Again, these messages assume a willing patient who shares the societal (ideological) view

sensible people do what is expected of them to stay healthy and fit for work. Moreover, a 'good' patient is accepting of their illness or condition, compliant with medical instructions and acquiesces to the requirements of the medical institution (Ferrie, 2010). Barry, Bradley, Britten, Stevenson and Barber (2000) also found doctor-patient consultations were generally conducted in the "voice of medicine" (p. 1250) and patients behaved in consultations as they were expected to behave rather than how they would have liked to behave. It was further reported the actions and beliefs of doctors influenced what patients said in consultations again suggesting medical ideology acts as a form of social control. Similarly, Martin (2014) contended the voice of medicine remains dominant in medicine because it is doctors who control the consultation and because both doctors and patients are socialised into particular ways of acting in medical consultations. This may occur because in medical discourse, the voice of the doctor is seen as factual, objective and active whereas patients' voices may be reduced to emotional and subjective qualifiers (Davis, 2008). The use of medical jargon and an emphasis on disease processes and specific body parts rather than the person further normalises medical techniques and endorses medical ideology about what is best for the patient (Bunton & Burrows, 1995; Martin, 2014).

Importantly, normalising medical techniques according to Bunton & Burrows (1995) reflected a change from medicine as care of the sick, injured and diseased to an institution which targeted the general 'healthy' population. Nettleton and Burrows (1998, p. 156) further identified a general consensus existed within medical literature that medicine had entered a new paradigm and was "generally governed by notions of surveillance or risk". Risk has become an increasingly prominent feature of modern medicine and popularisation of the language of risk is linked to ideological notions of health and health promotion (Peterson & Wilkinson, 2008).

Webster (2002) argued health surveillance, notions of risk and the capability to identify what conditions an individual is genetically predisposed to have blurred the boundaries between health and ill-health, increased the extent of the medical gaze and created patients without symptoms, occupying a “therapeutic limbo” (Webster, 2002, p. 445) which triggered more, rather than less uncertainty for these individuals. Western medical ideology is increasingly concerned with the ideology of “genetic determinism” (Finkler, 2000, p. 4) which in effect creates a breakdown of the body’s boundaries and allows medicine to enter into the lives of people who are not yet diagnosed with disease but rather are *at risk* of developing disease. Finkler (2000) contended women who belonged to breast cancer families were transformed from active beings to passive patients as a result of medical ideology of the genetic inheritance of disease. This is supported by Earle, Foley, Komaromy and Lloyd (2009) who drew attention to the changing nature of surveillance medicine and an increasing concern with health surveillance, biotechnology and geneticisation, issues which directly impact on the participants in this study and their families: the presence of a gene fault means women who are disease-free are also expected to fulfil the ideology of the compliant patient.

A Marxist analysis was necessary to illuminate the dominant ideological forces which impacted on the study participants and which created and maintained social order and processes. Ideology is sustained through various institutions, including the institution of medicine, and is reproduced in literary texts. Gendered divisions of labour in capitalist society situate women as nurturer and primary carer for the family and encourage women to make health decisions based on what is best for the family.

The success of capitalism is dependent upon a highly commodified society (Irvine, 2002). Capitalist ideology transforms goods, services and even the human body into commodities (Gerstein Pineau, 2011) which can be exchanged in the market

economy. In modern Western society, health care is no exception. Moody (2011) argued health care commodification occurred in tandem with the development of the modern hospital. Furthermore Moody (2011) claimed that the nature of contemporary medicine means hospitals compete for demand for health care services. Consultations, diagnoses, treatments and medical interventions are all argued to be commodities which have an associated value or price in return for improvements to health. Health care thus has an exchange value, that is, profit is able to be created because medicine has a use-value which people are willing to pay for, such as good health, freedom from disease and longevity. Health care becomes an act of exchange in the market system irrespective of the directness of payment whether it be direct-to-consumer payment, payment through health insurance schemes such as in Australia (Cancer Australia, 2015) or through 'single payer' schemes such as the UK NHS system (Moody, 2011) where the State is effectively the consumer, purchasing health services for its citizens. Particularly germane in the context of this study are issues of commodification of women, their bodies and genes, a critique of which now follows.

Commodification, genetics and the HBOC journey

The concept of the commodity is an important strand of Marxist critical theory. The term commodity pre-dates Marx and was used to refer to any entity considered useful or which satisfied human needs (Sammond, 2007). Marx developed the concept of commodity in relation to capitalism, arguing the market concealed the true nature of the production of goods by commodifying labour and the products of labour. A commodity is "an economically valued good within a relationship of exchange" (Hanson, 1999, p. 268). Marx used the term 'commodity fetishism' to describe the process whereby commodities are endowed with enigmatic and emblematic qualities which made them appear to be of value in themselves rather than for any utility or use-value (Jenkins, 2011). The usefulness of a commodity is determined by its physical properties whereas the value of a commodity is constituted by its social worth

(Thomas-Pollei, 2008). The value of a commodity is thus measured not only in monetary terms, but also for its exchange value. People come to desire and subsequently consume commodities, even when they have little use for them. The nature of capitalist society requires this because when commodities are fetishised, or fixated upon, people are prevented from seeing the reality of exploitation upon which capitalism is built (Sharp, 2000).

Lock and Nguyen (2010, p. 1711) define commodification as “the production or conversion of ideas, knowledge and objects into items which are considered useful and/or have exchange value”. The success of capitalism is dependent on the generation of profit so increasing commodification is an essential feature of capitalist societies (Allan, 1998). In the capitalist society, commodification of individuals occurs as people are reduced to objects with an associated monetary value in terms of ability to produce goods or social status.

A key requirement of commodification is alienation; “the capacity of a given commodity, and specific classes of commodity, to be physically and morally separated from their sellers” (Castree, 2003, p. 279). If a product or service is not able to be alienated, it is protected from market forces and the marketplace. This concept raises questions regarding the ownership of human bodies and body parts, including an individual’s genetic material (Andrews, 2006; Hanson, 1999, 2002). From this, until relatively recently, genes in particular were protected from market forces since they were unable to be alienated, or separated from their ‘owners’. However, advances in genetic and biotechnology now allow human genes to be isolated, cloned, copied and used for commercial purposes (Hanson, 2002; Thomas-Pollei, 2008) and therefore commodified.

Biotechnology is described as the science of using living things to produce goods and services (McCormick & Kautto, 2013). Parry (2008) concurs with Radin's (1987) seminal work which claimed the biotechnology-aided global marketplace for human body tissue and parts required a new conceptual framework for understanding commodification. Parry (2008) claimed such biotechnologies transformed body parts into artefacts which were able to be exchanged for money or other forms of currency such as academic prestige gained through biotechnological research. Biotechnologies are said to be transforming the bioeconomy; economic relations created through the latent value in biological materials (Birch, 2012). In contemporary Western society, biotechnologies are acknowledged and promoted as a significant source of new growth and wealth (Birch & Tyfield, 2013) and no more so than in the area of genomic medicine.

Although body commodification is not a new phenomenon (Sharp, 2000), contemporary definitions of commodification encompass previously unreachable areas such as cells, genes and genetic material and constitute an "alienation of inalienable goods" (Ryan, Team & Alexander, 2013, p. 471). Purdy (2001) contended commodification facilitated health care consumerism by creating new markets for medical products, services and technologies. Moreover, the creation of a new commodity, in this case genetic material, is a key tenet of capitalism (Birch & Tyfield, 2013; Zones, 2000). The commodification of 'new' pathologies thus creates potential new markets and generates further profit for corporate interests (Pryce, 2002; Thomas-Pollei, 2008).

The majority of breast/ovarian cancers occur for reasons other than inherited gene faults yet most current focus is on genetic causes (Conrad, 2005). A Marxist critique contends the focus on genetic causes of disease to the relative exclusion of other causes is necessary to justify the vast resources given to genetic endeavours

(Rosser, 2000). The technical ability to separate body organs, tissues, fluid and other appendages right down to a sub-cellular level effectively allows body parts to be isolated as objects, constructed as commodities and creates new potential sources of wealth for biotechnology and pharmaceutical industries (Acero, 2012; Baird, 2002; Cahill, 2001; Hanson, 1999, 2002; Thomas-Pollei, 2008; Lock & Nguyen, 2010; Rose, 2007). A critique of commodification from a Marxist stance was particularly relevant to this study since it raised questions about the relationship between commodification and nature and the effects of commodification on human experience.

Commodification of entities considered nature is not a new concept, for example, genetic engineering in agriculture has existed for some time (Cahill, 2001). Commodification of the human body in medicine likewise has a long history, from Burke and Hare's 'body snatching' of corpses for teaching human anatomy in the 19th century through to modern organ transplantation techniques (Lock & Nguyen, 2010). Similarly, the role of genetics in human disease has been explored using genetic technologies for some time (Baird, 2000). However, biotechnological advancements create a tension in health care (Hanson, 1999) because although individuals may benefit, such advancements are primarily developed for economic gain (Birch, 2012).

The Human Genome Project and subsequent gene sequencing technology has increased the scope of medical interventions in the form of genetic tests, gene manipulation and genetic therapies for the treatment of disease (Hanson, 2002). A significant part of this enterprise concerns testing for BRCA1 and BRCA2 mutations, one of the first genetic cancer tests to be widely marketed. This was not without substantial controversy owing to the patenting of these genes which led to the company Myriad Genetics gaining a monopoly of rights to genetic testing and therapeutic uses of the BRCA1 and 2 genes, essentially allowing ownership of these genes (Thomas-Pollei, 2008). The patenting and marketing of genes provides power

over the use of the genes and gives the patent holder exclusive rights to commercial exploitation (Thomas-Pollei, 2008). This raises important questions on who owns genes and genetic material (Castree, 2003) more so because the genetic industry is generally led by commercial interests who fund research and genetic services (Cahill, 2001).

Furthermore, since genes are essentially the most basic units of human life, the patenting of genes implies the ultimate commodification of human life (Hanson, 2002). From a Marxist stance then, genetic technologies and BRCA1/2 genes are able to be understood as marketable commodities which are protected through ideologies of empowerment and personal responsibility for health which trigger demand for wealth-generating medical services (Paul et al., 2014). Although the patent for BRCA1 and BRCA2 genes was eventually invalidated by the US Supreme Court in June 2013 (American Civil Liberties Union, 2013), the case nonetheless highlights the tension between the biological and non-biological identities of individuals and the question of who owns life.

The female body and commodification

Marxists argue commodification in capitalist society means people or objects are not valued in terms of what they can do (use value) but rather in terms of money or other commodities for which they can be exchanged (exchange value) or the status conferred by them (sign-exchange value) (Tyson, 2015). Since capitalist society depends upon consumerism, exchange and sign-exchange value are promoted as appropriate and natural ways of relating to the world. Tyson (2015) further explained capitalism promotes insecurity in order to promote consumerism and cites the increase in cosmetic surgery in the Western world as a symptom of this. Turner (2008) argued modern capitalist societies are essentially narcissistic and grounded in personalised consumption, under the guise of self-development and fulfilment. Self-

actualisation and increased self-esteem are able to be pursued through the purchase of commodities (Frank, 2002) which transcend materiality as a result of the hidden social meaning attached. People feel compelled to have the latest fashionable items, the whitest teeth, ageless skin, perfect breasts and such to feel good and worthy. Not only are these ideals sold to individuals, but individuals also feel the need to 'sell' themselves to be successful and to fit in to modern society (Tyson, 2015).

Cox (2011) contended capitalism produced normative notions of females and femininity which then became commodified and sold in the marketplace. The gendered structure of capitalism disproportionately targets and commodifies women who are then compelled to fit in with the idealised stereotype and thus "participate in their own objectification" (Cox, 2011; p. 20). In Western society, women are frequently reduced to descriptions of their bodies, a demeaning process which constructs women as objects rather than people and promotes a particular aesthetic in line with the patriarchal gaze (Twigg, 2000). The commodification of women and notions of normative gender fail to account for women who do not fit with the ideal aesthetic, either through choice or as a result of illness, disease or accident.

In relation to this study, it is reasoned that the female image is a marketable commodity and the image of the female as a product sells the concept of what is considered ideal female looks and behaviour. Moreover, the emphasis on the female breast as a symbol of femininity in Western society (Crompton, 2012; Davis 2008; Emilee, Ussher & Perz, 2010) accentuates the role breasts play in being a woman and reifies the importance of perfect breasts (Filc, 2004). The negative implications of this are illustrated by Ferguson (2000) who identified the 1980s saw the inception of a new disease of 'micromastia', or small breasts. Women with this 'disfiguring' condition could be 'cured' by cosmetic surgery which created breasts in keeping with the gendered ideal. Furthermore, the costs of breast augmentation may be subsidised by

the State through National Health Care plans, if women were psychologically distressed as a result of having small breasts, or viewed by surgeons as deviating significantly from the 'normal' breast size (Wilson, 2002) which again promotes commodification in relation to the female body and demonstrates medicine fulfils an ideological role.

More recently, Boulton and Malacrida (2012) highlighted the increasing normalisation of cosmetic breast surgery in Western culture, a culture which rewarded women who conformed to the image of idealised femininity and censured those who don't. Cosmetic surgery allows women to pay for breasts which conform to the Western ideal, the image of which can be sold literally and figuratively. For example, it may be asserted that there is no intrinsic good in surgically enlarging women's breasts: breast augmentation is undertaken purely to fulfil a socially constructed idealised body state and because idealised breasts are able to attract other values. A certain social status and "cultural valuation" (Ferguson, 2000, p. 83) is attached to having the ideal body/breasts and those not conforming to this ideal, including those who undergo mastectomy, have reduced sign-exchange value: in other words, the social value or worth of the female is assigned by humans in a particular given context. Hence when bodies and breasts are commodified, market forces permit interventions on the body to be undertaken not on the basis of inherent good, but to satisfy consumer demand based on socially and culturally constructed body ideals. Commodification and ideological practices coalesce here to allow this to happen because women have the financial means to fund surgery and surgeons are willing to insert foreign objects into women's bodies under the guise of personal autonomy and freedom of choice.

The prominence of breast reconstruction in definitions of breast cancer treatment further commodifies the breasts (Ferguson, 2000). From a Marxist perspective, ideologies of sexuality and femininity frame breast reconstruction as essential

following breast loss and allow the commodification of breasts to be expressed through the consumption of reconstructive surgery, hence is a significant source of wealth generation for some. Reconstruction is presented in ideology as an essential step in recovery from breast loss however equally it may be purported to be a process of commodification which aims to close the gap between the ideal and the actual body of the consumer. Frank (2002) reasoned this in itself was not problematic as all societies and cultures have within them a dominant body aesthetic of the time. The key issue, therefore, was a form of commodification which required the body to be fragmented so that different body parts can be incrementally improved through consumer activity in the form of reconstructive surgery.

To conclude this section, applying Marxist literary theory allows the text to be considered in terms of social, historical and cultural contexts which reflect the author's ideologies as well as those which are dominant in society. In this study, the Marxist concepts of ideology and commodification were particularly useful in constructing an understanding of the lives of high risk women as both construct understanding of the world and expose ways in which the HBOC journey is ideologically driven. From a Marxist perspective, medicine provides a service to women identified as high risk of developing breast/ovarian cancer by offering various interventions to diagnose and manage risk. Hence, a Marxist interpretation exposed ways in which HBOC acted as a source of economic gain for some by supporting ideologies of risk and offering surgery as the best approach to deal with the risk of cancer.

Foucauldian Literary Theory

Introduction

Foucault's work is complex, often controversial and at times obtuse. Although Foucault did not intend his work to be considered literary criticism, it impacted greatly on literary theorists owing to his argument power was located within language

(Bertens, 2008) making language one of the most significant forces in shaping human experience (Danaher, Schirato & Webb, 2000). Since literature is essentially language, it is not difficult to see why Foucault's work was of such importance to literary theorists. Bertens (2008, p. 123) further referred to the "hegemonic power" of language, including literature, underscoring Foucault's position that language was the site of social rather than textual power. In other words, power was not a result of the cleverness or accuracy of the text produced by novelists, doctors and the like, but rather was a result of the discourse created by them and to which they themselves claimed expertise (Culler, 2011).

An understanding of Foucault's theoretical and methodological contributions to modern literary and social theory highlights that Foucault did not attempt to provide an orthodoxy which scholars could apply to a particular area of concern to uncover the 'truth'. Rather, Foucault's influence encourages thinkers to question and problematise a situation, ideology, discourse or opinion in order new points of view may be created: to question what was considered as given or natural and seek solutions in the form of varying responses. Of particular relevance to this study is Foucault's critique of modern medicine and in particular the concepts of power and discourse and their associated techniques, since it was argued the participants in this study were involved in a process of negotiating competing dominant discourses and connected power relations in Western society which shaped and influenced experience, and ultimately decision making in relation to health. To this end, the following sections, elaborate upon key areas of concern in Foucault's work pertinent to this study.

Power, modernisation and Western medicine

The concept of power was central to much of Foucault's work because power relations were argued to be the means through which individuals in society were subjected, regulated, controlled and potentially emancipated (Lynch, 2011).

Foucault's theorising on modernisation and the rise of modern medicine conceptualised medicine in terms of power. In earlier sovereign states, classical forms of power were exercised through the right (of the King) to take life or let live (Taylor, 2011). Power forms were legislative, prohibitive and censoring and were wielded when individuals in society transgressed (Lilja & Vinthagen, 2014). However, the modernisation of Western society saw the emergence of the modern State as a political structure concerned with the needs of its people (Lynch, 2011). The modern State sought to admonish life rather than take life away hence in contrast to the sovereign state, power was the right to make live or let die (Taylor, 2011). Power in modern states then was less violent and coercive and more about the State's attempts to administer the welfare of its citizens (Murphy, 2003; Simons, 2013). For Foucault this represented a shift from sovereign power to biopower: the technologies developed during the eighteenth century in the new human sciences for managing populations (O'Farrell, 2007). Biopower can be understood as a form of life power which is exercised through techniques and technologies of and on the body which exert control through the interlocking and overlapping practises of discipline, surveillance and knowledge production (Klawiter, 2008). Biopower allows bodies to be disciplined at a societal level through managing the life and death processes of the population including births, deaths, reproduction and illnesses (O'Farrell, 2007).

Rabinow and Rose (2006) contended Foucault's concept of biopower originally polarised biopower into separate anatomo-political and biopolitical strands which dealt with disciplining and regulating of the body respectively. However as with other aspects of Foucault's work, there is ambiguity in terms of whether Foucault considered these strands as distinct, overlapping or inclusive of each other at different times in his writing. In general, there is consensus biopower is operated through the State whilst disciplinary power is operated through the institutions of the State (Taylor, 2011). Thus biopower can be understood as the task of governing entire populations

(Lilja & Vinthagen, 2014) and within this, disciplinary power can be understood as targeting individual bodies (Taylor, 2011). Disciplinary power is therefore incorporated within the mechanisms of biopower (O'Farrell, 2007) the overall aim being to maximise the potential and outputs of the body (Hoffman, 2011; Rabinow & Rose, 2006). Central to this are ways of knowing the body hence medicine is understood to take a prominent role in disciplinary power through its ability to expertly read and produce knowledge of the body.

Disciplinary power and Western medicine

Disciplinary power is a non-violent, non-coercive form of social control which utilises a range of power techniques and operates through various societal institutions including medicine, the family and education (Gutting, 2008). The overall aim is to produce obedient, capable citizens who can contribute effectively to the economic and political functions of the State (Gastaldo, 1997). Western medicine provides guidance on how people should understand, regulate and experience their bodies (Lilja & Vinthagen, 2014; Lupton, 1997), therefore disciplinary power operates through persuading people certain ways of being and acting are desirable to achieve good health. Part of this guidance relates to how women at risk of developing breast/ovarian cancer should act to prevent disease. Within Western medical discourse, this guidance leaves little scope for those who make decisions inconsistent with the aims of disciplining the body, such as high risk women who say no to RRS.

From a Foucauldian perspective, disciplinary power is able to be effected in medicine through three interlinking controlling techniques of hierarchical observation, normalisation and examination (Gutting, 2008; Hoffman, 2011). In this study, these techniques of disciplinary power were reasoned to be operating at both the macro and micro level as a result of the Human Genome Project. Widespread testing for genetic variation and disease opens up the body to a level of hierarchical observation and

scrutiny never seen before, adding a molecular gaze to the medical arsenal aimed at maximising body potential. The identification of gene faults which predispose individuals to certain forms of cancer (and other conditions) and the ability to test for them, has resulted in the development of guidelines for the classification and management of individuals based on the likelihood of disease development, including breast and ovarian cancer. These guidelines normalise the process by which women with a gene fault are targeted, classified and managed. The dominant medical discourse establishes how 'normal' women engage with the process and sets out the expected norms. This includes subjecting women and their bodies and genes to the medical examination so the truth about their particular situation can be uncovered thus securing future health. Data is collected on the outcomes from preventative interventions such as RRS, chemoprevention and ongoing screening for disease which adds to the growing body of expert knowledge about breast/ovarian cancer and further allows regulation and disciplining of bodies.

Attempts to influence individual behaviour and discipline bodies in relation to RRS can be understood as a part of the project of government which aims to protect the current and future health of the population. Biopower and disciplinary power are organised around normalising techniques which produce self-governing individuals and populations and persuade people of the sensibility of health interventions such as RRS for cancer risk. The power of medicine lies in the ability to take charge of the practices through which individuals seek to regulate and improve their health and consequently their daily lives. Moreover, the effects of disciplinary power are productive because knowledge of individuals is produced which is directly linked to 'official' knowledge, or "discourses of truth" (Foucault, 1980, p. 93) produced by the Human Sciences. In other words, disciplinary power exists in medicine because medicine knows 'the truth' about disease and how to avoid it. Foucault's analysis of power thus exposes the relationship between power relations, the production of

knowledge and the transformation of certain forms of knowledge into 'truths' which maintain disciplinary power. The next section elaborates on this relationship and draws attention to medical knowledge, power and 'the truth' and ways in which these regulate and discipline bodies in relation to cancer risk.

Power/knowledge and the 'truth'

Foucault argued against the notion of fixed absolutes awaiting discovery by experts and labelled as the 'truth'. Despite the connotations associated with the word 'truth', truth is not neutral, out-with or without power (Goldstein, 2003). Rather, the 'truth' is a product of power relations: "(...) truth is not by nature free - nor error servile (...) its production is thoroughly imbued with relations of power" (Foucault, 1978 p. 60). Importantly, since power relations exist within discourses, there can be no power without a discourse:

(...) in a society such as ours, but basically in any society, there are manifold relations of power which permeate, characterize and constitute the social body, and these relations of power cannot themselves be established, consolidated nor implemented without the production, accumulation, circulation and functioning of a discourse. There can be no possible exercise of power without certain economy of discourses of truth which operates through and on the basis of this association. We [sic] are subjected to the production of truth through power and we [sic] cannot exercise power except through the production of truth. (Foucault 1978, p. 93)

Foucault's argument power, knowledge and truth are inextricably linked and the individual- as-subject is created within this knowledge-power relationship is clearly articulated above. On this point, Foucault concurred with earlier work of Nietzsche (1873), who problematised the objectivity of truth and held it was power, as opposed to knowledge, which shaped the truth. Power and knowledge have the same goal: simply, knowledge means power and power allows one to know. The positive potential of power is also identified because once knowledge is known; one has the power to act.

Foucault further theorised on power/knowledge and truth in relation to medicine in *The Birth of the Clinic* (1973) in which he constructed an historical and critical analysis of the development of modern medicine. Foucault argued the focus of medicine shifted with the emergence of clinical medicine in the late 18th century. Modern medicine had the power to look deep inside the body, look beyond the symptoms of disease and develop new understandings of how the body functioned in health and disease. Foucault used the term “medical gaze” (Foucault, 1973, p. xiv) to describe the dehumanising separation of the body from the person (identity) (Kendall, 2011) which resulted from the search to uncover truths about the body. Increasingly, modern technologies can be understood as expanding the medical gaze through genetic testing for presymptomatic disease such as HBOC.

Foucault did not deny there were verifiable truths which could be found within the natural sciences, nor that medical knowledge lacked scientific validity, rather he opposed the ways in which (scientific) knowledge and expertise led to a privilege which became power: power of experts over non-experts arising from an acceptance scientific knowledge was somehow more truth-like and superior to other forms of knowledge. The creation of scientific knowledge propagated as ‘truths’ or ‘facts’ about the human body enabled the body to be disciplined and the population to be studied and regulated by ‘experts’. In contrast, Foucault believed that knowledge of the body was unstable and humans were too complex to be isolated into separate parts for investigation thus no legitimate, decisive ‘truth’ about the individual could ever be gained (Foucault, 1968). For Foucault, ‘truths’ were historical events, not absolutes awaiting discovery (O’Farrell, 2007).

The medical gaze not only constructed the body and body parts as objects of knowledge, it also allowed the knowers of such information to be constructed in a particular way (O’Farrell, 2007). Foucault argued the medical gaze was supported by

an increasingly sophisticated language which conferred a growing knowledge of facts and truths about the human body and thus allowed the creation of a “scientifically structured discourse about an individual” (Foucault, 1973, p. xiv). The discourse which supported the medical gaze was of crucial importance because power is fundamentally discursive (Lynch, 2011). That is, power operates through what people say as much as what they do. This leads on to the next section in this thesis which introduces Foucault’s concept of discourse and how discourses give rise to power relations through the creation of knowledge and truths about objects of concern in Western society.

Foucault’s concept of discourse

Foucault’s work on discourse has been described as his most significant contribution to critical inquiry (Vighi & Feldner, 2007). In the *Archaeology of Knowledge*, Foucault (1972, p. 107), proposed discourse is “a group of statements which belong to a single system of formation”. A statement is not the words themselves, but rather the rules which make the words meaningful: in other words, provide discursive meaning. Statements are thus the basic units of discourse and create relationships with other statements which provide context for the discourse (Danaher et al., 2000). Systems of formation refer to a “complex group of relations that function as a rule” (Foucault, 1972, p. 74) and relate to a collection of institutions, social groups and relations between discourses. Significantly, the system of formation is not external to the discourse but rather resides within it and in effect, it creates its own existence.

For Foucault, there existed a difference between what could be said using appropriate logic and language, and what one actually says: “(...) discourse is constituted by the difference between what one could say correctly at one period [under the rules of grammar and logic], and what is actually said” (Foucault, 1968, p. 63). In other words, conversations reflect what people feel can and cannot be said under particular

conventions, thus Foucault was able to speak of a clinical discourse, an economic discourse, a psychiatric discourse and so forth. For example, it would be logical and grammatically correct to say to a woman 'please remove your clothes from the waist up'. However, it is unlikely such a statement would be acceptable during social discourse, whereas it may form part of a patient examination in medical discourse. Discourse then is identified as an activity or practice, bound by certain rules and which co-exist in a world of other (competing) discourses. Multiple discourses exist within modern societies but some discourses are dominant to others. Dominant discourses are those which operate through established institutions such as medicine, the family and the law and although dominant, are under constant challenge owing to the unstable nature of knowledge (Manias & Street, 2000).

In relation to this study, a cancer discourse exists (Armstrong, 2007; Davis, 2008; Harrington, 2012; Reisfield & Wilson, 2004) which establishes how people should act when faced with cancer and gives consent to certain ways of speaking about the disease. Although fear and uncertainty are acknowledged, the cancer discourse reflects the dominance of the medical perspective as the only appropriate way of managing the disease (Clarke & Everest, 2006). Notably, the cancer discourse is replete with metaphor which may influence the experience of the disease (Davis, 2008; Harrington, 2012; Reisfield & Wilson, 2004). War/military metaphor (Clarke & Everest, 2006; Cobb & Starr, 2012; Grant & Hundley, 2008; Haines et al., 2010; Reisfield & Wilson, 2004), sporting metaphor (Grant & Hundley, 2008; Seale, 2001) and journey metaphor (Harrington, 2012; Reisfield & Wilson, 2004) are commonly applied which promote a certain way of talking about cancer and confer an accepted set of underpinning values and expectations (Davis, 2008). These dictate people exhibit a positive outlook, fight the disease, engage with treatment interventions, win the war on cancer and become cancer survivors (S. King, 2004; Sulik, 2012). Doubts about the efficacy of treatment, refusing treatment, pessimistic thoughts and generally

'lying down' or giving in to the disease are not viewed as worthy attributes and are less likely to be verbalised (Davis, 2008). It is a discourse of encouragement, consent and cooperation which imposes a moral imperative on the person with cancer (Sulik, 2012; Wilkinson, 2001). In particular, Crabb (2006, p. 103) described the breast cancer discourse as a "discourse of responsibility" which obliges women to partake in health practices such as breast cancer screening in order to create health benefits for themselves, their families and the wider community. Hence, discourse creates a "culture of conformity" (Jones et al., 2005, p. 378) in which the patient is unquestioning and compliant. The cancer discourse suggests patients who do not conform to this ideal are uninformed, mistaken or foolish (Crabb, 2006; Davis 2008).

Discourse provides the means by which knowledge about a particular topic at a particular time in history can be spoken. For Foucault, discourse creates meaning therefore knowledge of anything is only meaningful within a discourse (Hall, 2004). Furthermore, dominant discourses, such as the medical discourse, are those which determine what knowledge is considered important and of value (Manias & Street, 2000). For example, although cancer is an organic disease, it only exists meaningfully within a discourse about it: it is the discourse, not the disease itself, which produces knowledge of it. In other words, breast and ovarian cancer exist but only take on meaning when they become objects of knowledge within a discourse. The dominance of medical and genetic discourses ensures the authority of genetic, medical and scientific knowledge and statistical data in relation to breast/ovarian cancer risk, effectively equating risk of disease with inevitability of disease (Armstrong, 1995; Crabb, 2006). Women with a positive genetic test are described by statements such as 'high risk', 'gene carriers', 'genetically pre-disposed to developing cancer' 'faulty gene carriers' and the like. RRS is constructed in medical discourse as not only a reasonable option for high risk women (Crabb, 2006) but is put forward as the primary intervention for reducing risk and securing a disease free future (Ingham et al., 2013).

The medical discourse thus sets out a problem and a proposed solution which serves to organise and regulate women with a family history of breast/ovarian cancer.

Hall (2004, p. 347) further contended knowledge and 'truth' were "historicised" by Foucault's position that knowledge or 'truth' about anything only applied within a specific historical context. Moreover, from a Foucauldian perspective, the fluidity of discourse is more to do with power than logic as change occurs because those who create the discourse also have the power to make it true.

This highlights the temporality of discourses which Foucault (1972) believed were shaped by the 'episteme' or 'world view' in which they existed. The existence of the rules of discourse and historical and cultural affiliations mean discourse both creates and sustains social norms by establishing knowledge or 'truth'. This is expressed through language and governs how individuals should behave within a particular discourse; therefore, it is a form of power. In other words, discourse is the site at which truths and power relations are produced (Foucault, 1968). Moreover, discourse creates the means by which the body can be socially controlled, disciplined and regulated. In keeping with this analysis, Crabb (2006) argued the analysis of discourse allowed a critique of ways in which individuals were constructed and talked about in discourse. Thus, both body and mind are governed by hidden historical and culture-bound rules which determine what is said (or not) and how it is said within discourses. Foucault (1972, p. 49) referred to these as discursive practices which "systematically form the objects of which they speak".

Discursive practices

Discursive practices are rules which constitute how discourses are formed (Manias & Street, 2000). These practices are ways of talking which serve as collective organising tools, sanctioning certain actions and compelling individuals to behave in

certain ways within discourses. Power is a direct result of discursive practices which are created within a discourse (Bertens, 2008).

Foucault's notion of discursive practices was influenced by the work of Heidegger (1889 – 1976) regarding the interpretation of everyday practices (Dreyfus, 2004; Dreyfus & Rabinow, 1983). In Heidegger's notion of *being*, humans are seen to be formed within certain cultural and historical conditions which provide a contextualised background against which humans interpret everyday life and become socialised (Dreyfus & Rabinow, 1983). Importantly, those existing and functioning within these shared practices are unaware of them unless made aware through the actions or words of others. Similarly, Foucault argued social and official institutions and associated discourses support discursive practices which created accepted norms and legitimised subjects and behaviours, against which individuals unknowingly interpreted their everyday lives (Dreyfus & Rabinow, 1983). Thus, discourses are power relations and discursive practices ensure order by directing humans to do what is expected in given situations.

In Western medical discourse, power operates through discursive practices which compel individuals to act in certain ways to protect health. Crabb (2006, p. 175) referred to discursive practices as "rhetorical devices" which constructed certain preventative strategies, including RRS, as good, responsible and rational actions which indicated to high risk women what is expected in their given situation. Similarly, genetics can be understood as a discursive practice which reinforces the medical gaze and subtly persuades individuals to engage with risk reducing interventions in order to self-regulate and protect health. From a Foucauldian perspective, self-regulation is more effective than coercive techniques in controlling people as resources or policing are not required and resentment is avoided.

To sum up then, discursive practices enable power relations because power is asserted through language and the ways things are spoken about. However, the nature of power is such that discursive practices both enable and inhibit, because what constitutes the truth is unstable and contingent.

Power and resistance

The centrality of power in Foucault's work was introduced earlier in this section. Foucault argued the individual-as-subject could not be separated from the complex power relations within which the subject is placed (Foucault, 1982). Central to Foucault's argument is power is not a *thing*, and power does not exist until it is put into action. Rather, power is a relation, a way in which certain actions modified others: "[power is] a set of actions upon other actions" (Foucault, 1982, p. 789) therefore power is exercised rather than possessed (Manias & Street, 2000). This is an important concept because it underscores power as relative and dynamic hence Foucault was able to defend against critics who posited his analysis of power was suffused with pessimism and rendered the subject repressed and impotent.

Foucault rejected conceptualisations of power which supported the futility of resistance (Lilja & Vinthagen, 2014) and posited power dynamics mean different responses to power were available hence resistance to power was not only possible, but inevitable. Power and resistance are allied rather than oppositional because resistance is shaped by power relations and power relations are also, paradoxically reinforced through resistance (Lilja & Vinthagen, 2014). If resistance was not possible, if there existed only one way of acting, power could not be exercised and would not exist. For Foucault, freedom was a condition of power: "freedom must exist for power to be exerted" (Foucault, 1982, p. 790). Thus individuals are constituted as subjects through power relations but are also capable of deliberate self-transformation through resistance to power relations (Allen, 2008). Individuals may resist power through

marginalised discursive views which disrupt dominant discourses hence power can be both repressive and productive (Manias & Street, 2000; Simons, 2013). Foucault (1982) maintained that resistance to power was thus a legitimate and sensible basis for understanding what power relations exist, where they exist, when they exist and how they function.

If one accepts Foucault's definition of power as being a relation and a set of actions upon other actions, then one sees all societies have power relations embedded within them. Not only from legal, constitutional or institutional perspective, but also from a social perspective since living in a society necessitates the actions of an individual can and do modify the actions of other individuals. For example, in the medical encounter, the actions of doctors bring about actions in patients as a result of power relations supported by a dominant of medical discourse which is internalised and acted upon (Lupton, 1997). Thus, power is not something held by one group and exerted over another: rather, it is a relationship in which all take a role, making power an intrinsic and omnipresent feature of human societies. It is the power relations in everyday life which categorises and transforms individuals into subjects (Allen, 2008). In this study, the power relations in which the participants took a role and ways in which the participants yielded to or resisted such relations are exposed. This created an understanding of how the participants negotiated power relations and created individual subject positions, often at odds with the dominant discourse.

To conclude this section, Foucauldian literary critique encourages researchers to ask questions of the text in order to problematise the taken-for-granted, the given and the ostensible so that alternate points of view may be offered to illuminate a broader understanding of society. To understand Foucault's contribution to literary theory, one must deliberate his views on power and power relations. Foucault's key concern was the culture of the self and how individuals come to constitute themselves as subjects

in society. Foucault's focus was the relationship between power relations and the production of knowledge, and the transformation of certain forms of knowledge into 'truth' which led to power and subjectification.

Foucault's analysis of power articulates historical forms of power from pre-modern coercive and often violent modes of power to modern modes of power including biopower and disciplinary power which regulated and disciplined bodies. Power is relational because power/knowledge regimes differ in their application and effectiveness. Power and knowledge are irrevocably intertwined because knowledge allows an authoritative truth to be presented and simultaneously validates itself as the truth. Medicine is understood as a discourse which is deployed as an instrument of power which disciplines the body because the medical discourse is expert and lays claim to knowledge of the truth about the body. Despite the authority of the medical discourse, the unstable nature of knowledge/power means power relations are able to produce both positive and negative actions, truth and error hence resistance to medical authority is possible.

In relation to this study, application of a Foucauldian critique was useful in understanding how dominant discourses about women's bodies combined with accepted health care practices allow medicine to define what is good for the bodies of women at risk of cancer. Problematic to this approach is it fails to account for those who do not share the common goal, or those for whichever reason, demonstrate resistance to the dominant Western medical discourse who were the focus of this study. The participants in this study were seen as being non-compliant however it was contended they are only non-compliant within the construct of the dominant medical discourse and that other discourses are available to help shape understanding of their experiences.

Feminist Literary Theory

Introduction

The methodological approach taken in this study posited the experiences of high risk women who refuse RRS cannot be divorced from social, cultural and historical influences on the experiences which influence the decision to say no to surgery. A central premise was the female breast is symbolic of the idealised female body in Western society, a society which “exults in breasts” (Cromptvoets, 2006, p. 79) and which is “breast obsessed” (Thomas, 2006, p. 350). Western values and traditions in relation to the breasts serve to oppress women because such messages imply without breasts, women are not whole (Thomas, 2006). Similarly, the female ovaries are the fundamental symbol of womanhood (Gubar, 2012) and as such are associated with femaleness, femininity and sexuality. Ovarian loss is associated with negative effects on body image, gender and personal identity (Hallowell et al., 2012) and may induce a feeling of being an incomplete woman (Fry et al., 2001a). Moreover, it was contended Western society is a patriarchal society in which all human social experience is gendered (Landman, 2006), therefore the participants’ stories could not be voiced without reference to the dynamics of gender (Thomas, 2006).

The patriarchal nature of Western culture is both causative and symptomatic of the gendered text therefore using feminist literary theory allowed an analysis of the text and the world in which it was read. Potts (2000) argued a feminist analysis gives voice to women in relation to the experience of cancer, threat or actuality, and exposes the socially constructed meanings attributed to breast/ovarian cancer which impact on all women’s lives in Western society. Research examining decision making in relation to cancer management has largely failed to take gender differences into account despite the distinctiveness of women’s health problems (Szumacher, 2006). Szumacher (2006) further claimed the unique nature of breast cancer and breast loss meant studies examining decision making in this arena must address the issue from a

female perspective. Consequently a feminist literary approach was applicable in this study and allowed an examination of ways in which women are constructed in Western society which can impact on health related decision making (Thomas, 2006). Taking a feminist perspective lent itself to an examination of the public and private folklore of the study participants to understand their life experiences within this context.

Overview of feminist literary theory

At the simplest level, feminist literary theory poses questions relating to power relationships in literature and other cultural productions to gain a clearer understanding of the social reality of women (Allen, 2014). The text is analysed for textual constructions of gendered meaning (Keating, 2005) which reveal power relationships which impact the lives of women (Brizee, Tompkins & Chernouski, 2011).

Feminist literary theory is complex and draws on a range of other critical theories including psychoanalysis, Marxism and post-structuralism (Keating, 2005). However, common to all is the aim to challenge forms of domination and power which subordinate women and all seek to give women more control over their own lives (Easton, 1996; Willard, 2005). Millet's 'Sexual Politics' (1970) is credited with being the first widely read book of feminist literary criticism. It included a critique of capitalism and patriarchy and ways in which both sought to control women. Millet (1970) distinguished between 'sex' as biological and 'gender' as socially constructed, hence 'feminine' characteristics were products of culture rather than biologically determined. More recently, Klinge and Bosch (2005) also distinguished between the biology of 'sex' and the socially constructed 'gender', arguing both concepts are equally important in health-related research.

The following sections elaborate on feminist literary theory in relation to key areas of concern in this study. Notably, ways in which Western values and traditions in relation to the breasts and ovaries serve to oppress and control women are explored by focussing on social constructions of the female role/femininity and breast/ovarian cancer. The patriarchal nature of Western medicine is also considered and the feminist concept of resistance is discussed with reference to power struggles and ways in which resistance to normalising strategies and regulations is possible through the body.

The female role and femininity in Western society

A key focus of feminist literary theory is how the female role, femininity and womanhood are constructed in Western society. A feminist stance contends female characteristics are socially constructed rather than biologically determined: “masculinity and femininity are not predetermined by the body itself, but are constructed within culture” (Warhol-Down & Herndl, 1997, p. xi). Adopting a feminist stance then challenges biological conceptions of female identity which define women according to reproductive physiology (A. King, 2004) and suggest a woman’s primary role is as mother and caregiver (Willard, 2005). Instead, ways in which male and female genders are socially constructed and the privileging of the male gender are critiqued and challenged (McAfee, 2014; Tyson, 2015).

A feminist stance reasoned the participants in this study were exposed to gender ideologies and heteronormative values in Western society which assign certain attributes and roles to women and men. Gender is argued to be a powerful method of social control which both produces and restricts bodies (A. King, 2004). A. King (2004) further claimed women’s bodies are disproportionately judged and valued for appearance hence women are subjugated through their bodies. Women are socialised into a particular role in Western society through ideological messages

transmitted from an early age (Thomas, 2006; Tyson, 2015) which convey how women should conform to Western notions of beauty and sexual attractiveness and be maternal (Ferguson & Kasper, 2000). Women are expected and encouraged to be the object of the male gaze hence experience of breast loss is necessarily tied to a cultural emphasis on the breasts as objects of male sexual interest (Szumacher, 2006).

Considerable effort has been devoted to examining the role the breasts/ovaries play in defining femininity. The female breast in particular symbolises sexuality, femininity and motherhood in Western society (Ehlers & Krupar, 2012; Lantz & Booth, 1998; Thomas, 2006; Schulzke, 2011). Influential social anthropologist Margaret Mead referred to the female breast as “the primary source of female identity” (Mead, 1949, cited in Thomas, 2006, p. 363) in Western culture and having breasts serves as a public display of femininity (Chan, 2010; Hallowell, 1998, 2000; Saywell, Beattie & Henderson, 2000; Spadola, 1998). Similarly, ovaries symbolise womanhood and as such are associated with femininity and sexuality (Hallowell et al., 2012; Gubar, 2012). Overall, women largely define themselves in opposition to traditional male characteristics (Ferguson & Kasper, 2000) as a result of essentialist ideology which reinforces the biological differences between genders (Sischo, 2008; Tyson, 2015).

In relation to this study, cultural norms impose standards of femininity onto women and give ‘feminine’ characteristics a natural authenticity, one of which is having two breasts and ovaries. Women who appear to have diseased breasts/ovaries or no breasts/ovaries may be viewed as ‘unfeminine’ (Emilee et al., 2010) or ‘abnormal’ (Cromptoets, 2012). Mastectomy has been described as a “violation of femininity” (Saywell et al., 2000, p. 38) and oophorectomy as an “insult to femininity” (Ferrell, Smith, Juarez & Melancon, 2003, p. 253) highlighting the key role these organs play in defining femininity in Western society. Breast loss in particular is consistently referred

to as disfigurement and mutilation (Szumacher, 2006), therefore it is not surprising loss or potential loss of the breasts and/or ovaries can invoke great turmoil in women as they seek to understand their altered bodies which contrast with societal norms.

It has also been claimed prosthesis use and post-mastectomy reconstruction endorses and maintains gendered norms which subordinate women (Báez-Hernández, 2009). Reconstruction is framed in medical and public discourse as an essential procedure following breast loss on the grounds it can help women adapt to surgery (Crompvoets, 2006; Guillem et al., 2006; Haines et al., 2010; Sulik, 2012). Rubin and Tanenbaum (2011, p. 407) used the term “pinkwashed” to describe a breast cancer culture in which prosthesis-wearing or post-mastectomy reconstruction is mandatory in order to avoid appearing radical or oppositional to societal norms about how women should look. In relation to breast loss and reconstruction, women in Western society face a paradox: non-reconstructed women may be viewed as desexualised and oppositional whereas those who do undergo reconstruction face further surgery, pain and discomfort and ironically may be viewed as supporting women’s objectification by complying with dominant heteronormative notions of femininity (Rubin & Tanenbaum, 2011). Failure to adequately place breast reconstruction within its cultural and social contexts helps reproduce oppressive normative standards for women because the ‘need’ to have reconstruction goes largely unchallenged.

Drawing on feminist insights therefore highlighted the conflict and contradictions women in Western society face with respect to the loss of the breasts and ovaries. On the one hand, these organs symbolise femininity and womanhood and Western society expects women to possess them. Simultaneously, Western discourse demands women keep themselves healthy, nurture the family and generally conform to what is expected of the female role (Gibbon, 2006). Such contradictions have been

discussed by various scholars. Kasper (1994) stated discrepancies existed between societal expectations of women imposed by dominant cultural processes and women's own definitions of self gained through life experience. Women facing breast loss face a dilemma because taking control of cancer risk through RRS exposes women to other significant losses including perceived loss of self-identity, femininity and sexual attractiveness (Hallowell, 2000). Szumacher (2006) drew attention to the paradox experienced by women facing breast loss who were expected to conform to cultural standards of beauty yet maintain autonomy over their bodies when making health-related decisions. Thomas (2006) similarly identified societal contradictions often made it difficult for women to distinguish between personally and culturally embedded feelings about their breasts. These contradictions were spoken and unspoken, revealed and hidden and emanated from a variety of sources including the media, parents, peers partners, the medical system and Western society in general. Thomas (2006, p. 367) used the term "ring of silence" to describe these contradictory messages. Thomas (2006) contended these functioned as oppressive norms which distorted definitions of womanhood and influenced women's decision making with regard to participation in breast health initiatives.

Thus an analysis of the social construction of femininity and the female role in Western society provided insight into some of the covert influences which may impact women's health related behaviours particularly in relation to their breasts and ovaries. The next section explores the social construction of breast/ovarian cancer from a feminist literary stance and discusses the potential impact of this on women diagnosed with a high risk of developing breast/ovarian cancer.

Social constructions of breast/ovarian cancer and its management: a feminist perspective

In this study, it was argued a significant social investment in the female breasts and ovaries existed which allowed others a legitimate say in what happened to these organs. This is reflected in research which found decision making in relation to surgery for breast/ovarian cancer and cancer risk is frequently framed within the context of the woman's personal/sexual relationships and familial obligations (Crabb, 2006; Gibbon 2006; Sheppard & Ely, 2008; Rubin & Tanenbaum, 2011; Weiner, 2011; Zagouri et al., 2013) and the consequences of treatment on others, for example children and partners (Acero, 2012; Howard et al., 2011; Lloyd et al., 2000; Rowley, 2005). This research underscores how women are expected to consider the needs of others when making health related decisions in relation to cancer risk. In this sense, the breasts and ovaries of high risk women can be understood as belonging not only to the women themselves, but also to their significant others vis-à-vis their obligations to stay healthy for the sake of others by having their breasts/ovaries removed.

A feminist perspective contends historically women's bodies have been invaded, possessed and occupied by others as a result of enduring patriarchy in society (Acero, 2012). Ownership of the female breasts has been appropriated by agencies other than the women to which they belong (Szumacher, 2006). Spadola (1998) described the breasts as the most public of private parts, as manifested by initiatives such as breast screening programmes, breast feeding programmes and indeed in initiatives surrounding RRS for HBOC. Women's breasts are also argued to be subject to a greater degree of public scrutiny and evaluation than any other body part (Chan, 2010) emphasising their importance in social discourse. It is this prominence in Western society of the female breast and to a lesser extent the ovary, as signifiers of femininity, sexuality and womanliness which add a complex layer to decision making around RRS. Moreover, such social constructions situate decision-making in

response to cancer risk as both within and out-with the medical arena. Although the medical discourse outlines what to do in response to cancer risk, social constructions of the disease and its management bear significant weight for women identified as high risk.

Social constructions of breast cancer shape the way women experience breast cancer including decision making in response to therapeutic interventions (Szumacher, 2006; Thorne & Murray, 2000). In this study, this extended to women diagnosed with a high risk of developing breast/ovarian cancer because these women were exposed to images and constructions of breast/ovarian cancer which were influenced by cultural and societal contexts. Integral to these were perceptions of female norms and femininity. Breast/ovarian cancer threaten such perceptions by assaulting the female body physically and emotionally to the extent women facing breast cancer may fear the loss of the breasts more than loss of life (Davis, 2008; Ferguson & Kasper, 2000). In Western society, breast cancer is often depicted as a cosmetic rather than physical crisis because breast loss is constructed as an emotional loss (Rubin & Tanenbaum, 2011) and a loss of sexual attractiveness (Szumacher, 2006). Indeed the threat to life caused by breast cancer is often overlooked in favour of the threat to female identity, sexuality and body image (Thorne & Murray, 2000) which paradoxically endorses gendered norms about how women should think and be.

Studies examining the representation of breast/ovarian cancer expose the unstable and potentially oppressive nature of the breast/ovarian cancer discourse. The majority of work has focussed on how breast cancer is represented (Crompton, 2006; Thomas, 2006). Earlier studies in Australia (Lupton, 1994) and the USA (Lantz & Booth, 1998) revealed breast cancer was consistently constructed as a disease of epidemic proportions caused by 'lifestyle' factors such as alcohol consumption, obesity, use of oral contraceptives, delaying pregnancy and abstaining from breast-

feeding. The link between oestrogen exposure and breast cancer development was acknowledged; significantly, Lupton (1994) and Lantz and Booth (1998) expressed concern at the way this association was linked to female social behaviours to create an image of breast cancer as epidemic and a crisis situation. The authors posited the emphasis on a woman's role in engaging in such 'risky' lifestyle 'choices' resulted in victim-blaming and drew attention away from other potential causes of oestrogen exposure which may promote cancer development.

More recent work suggests an oppressive and punitive discourse persists in relation to breast cancer. In addition to blame attributed to women through risky lifestyles, discourses of positivity, silence and concealment place a moral imperative on women to conform to normative standards which are oppressive and can lead to victim-blaming (Wilkinson, 2001). Cultural configurations of breast cancer have changed significantly over the past four decades from a stigmatised, private disease to a disease of epidemic proportions requiring public and political debate (S. King, 2004). Mass media attention to selected aspects of breast cancer presents a skewed reality which promotes an overly optimistic focus on survivorship and leaves little room for those who do not engage with the dominant discourse. S. King (2004) further claimed this was problematic as it diverted attention away from other significant issues such as the continuing number of women dying from breast/ovarian cancer, lack of universal health care and lack of research on environmental causes of the disease. Likewise, Sulik (2012, p. 16) found themes of victim-blaming persisted through survivorship ideology which allowed blame to fall on women who failed to adopt the "she-ro" role necessary for bravely battling the disease and accompanying disfigurement.

Although lifestyle factors still feature heavily in breast/ovarian cancer discourse, increasingly genetic causes of disease take precedence (Conrad, 2005; Finkler, 2000; Lemke 2002; Lock & Nguyen, 2010; Riska, 2003; Wills, 2005). One might argue the

emphasis on genetic causes of disease rather than lifestyle 'choices' suggests breast/ovarian cancer occurs for reasons outside a woman's personal control. However, the prominence of genetic causes appears to have done little to negate the victim-blaming messages so frequently attached to breast/ovarian cancer discourse (Silverman et al., 2001; Szumacher, 2006; Wilkinson, 2001). One reason for this relates to the ascribed female role in Western society as discussed earlier in this section. Women are constructed in dominant discourse as carers and nurturers (Gibbon, 2007; A. King, 2004), who are responsible for the health of the family (Acero, 2012; Kasper & Ferguson, 2000; Szumacher, 2006). A key part of this role then is staying healthy for the sake of others. Responsibility for the disease is also placed onto women through their requirement to engage with interventions to detect and manage the cancer (Griffiths et al., 2010). Hence whilst women may not be held responsible for owning a genetic mutation, personal responsibility for risk is embedded within medical discourse (Ilkilic, 2009; Lupton, 2006; Robertson, 2000) and it is likely women will be considered culpable when action to reduce the risk of cancer, such as RRS, is refused (Hallowell & Lawton, 2002; Resnik, 2014).

A feminist critique suggests common to all social constructions and cultural configurations of breast/ovarian cancer is an underpinning ideology that non-compliance with the traditional female role is instrumental in the development of breast/ovarian cancer in women. Social constructions of breast/ovarian cancer are a conduit for communicating ideas, values and fears and reflect broader messages about social boundaries and power in society generally (Acero, 2012; Lantz & Booth, 1998). From this, an understanding of the ways in which power emerges and is used and misused is gained (McAfee, 2014) because women are required to make decisions in response to breast/ovarian cancer risk within a discourse of medical hegemony and its accompanying power structures (Szumacher, 2006).

The next section focuses on an analysis of the institution of medicine from a feminist perspective and exposes ways in which genetic/risk ideologies and gender biases in medical discourse coalesce to construct power relations which may oppress high risk women facing RRS.

Western medicine, patriarchy and power

The institution of medicine has been central to feminist theorising since the body is the site of most gendered interaction (Bilton et al., 2002; Turner, 2008). Throughout history, women's bodies have been relegated in medicine, the reproductive organs in particular considered intrinsically pathological (Tyson, 2015; Wilkinson, 2001). In Victorian times, the uterus was considered the controlling organ of the female body. Disorders of the female reproductive system were believed to cause a range of conditions including insanity, dyspepsia, rheumatism, cardiac inadequacy and the frequently diagnosed 'hysteria' (Thorne & Murray, 2000).

A feminist critique of modern Western medicine draws attention to the scientific, empiricist roots of the biomedical model (Willard, 2005; Wylie et al., 2012). Francis Bacon (1561 – 1626) is commonly credited with being the founder of modern science and is said to have believed the mind to be masculine and nature to be feminine (Darlington, 2010). Medicine is therefore able to be understood as the (male) power of the mind/medicine over (female) nature (A. King, 2004). Moreover, the biomedical model of medicine is underpinned by the assumption all illness is secondary to pathological disorder or disease, therefore removal or amelioration of disease will return the person to health (Wade & Halligan, 2004). The focus of the biomedical model is the body in disease rather than the well-being of people and their bodies.

Medicine reflects and reinforces gender divisions in Western society by positioning women in terms of their ability to fulfil the traditional female role of homemaker and

nurturer (Gibbon, 2007; Kennedy & Kennedy, 2010). Medical literature also has a tendency to classify medical issues by gender (Griffiths et al., 2010). For example, depression, anxiety and insomnia are regarded as problematic in women whereas industrial and sporting injuries are associated with men (Bilton et al., 2002). The objective medical gaze positions women as subjects in the system of medicine (Gray, 2007) and has medicalised normal female events including menstruation, pregnancy and childbirth (Purdy, 2001; Riessman, 1983; Willard, 2005; Wylie et al., 2012). This has created the means to control women's sexual expression and reproductive capacity through the regulation of women's bodies (Bilton et al., 2002; Lerner, 2000).

A feminist analysis of Western medicine highlights other patriarchal practices which serve to oppress women. Prior to 1994, women were largely excluded from clinical trials to assess the safety and efficacy of new medicines which meant medicines prescribed for women had only been tested on men (Holdcroft, 2007; Tyson, 2015). So-called women's symptoms have been trivialised in medicine which has generally neglected health issues of concern to women (Klinge & Bosch, 2005). With regard to treatment for breast cancer, less mutilating alternatives to the radical mastectomy were not explored until relatively recently in part owing to the prestige afforded to surgeons who carried out the technically complex yet debilitating surgical procedure (Löwy, 2010). Löwy (2010) further claimed the use of RRS to remove healthy breasts and ovaries in some ways represented a return to the type of surgical radicalism for cancer risk as exemplified by the radical and grossly debilitating Halsted mastectomy. Medicine is also a key stakeholder in the surgical modification of women's bodies through cosmetic and reconstructive techniques (Sulik, 2012), notably those performed on women's breasts in order to conform to socially constructed ideals of women's bodies (Crompvoets, 2012).

Feminist perspectives on the prominence of genetic medicine are also valuable because genetics raises issues of significant concern for women including reproduction, embodiment, choice and agency (Ettorre, Katz Rothman & Steinberg, 2006). Within the biomedical model, the genetics discourse reduces high risk women's bodies to faulty genes. Medical intervention thus takes primacy and social, cultural and individual perceptions and circumstances which influence the experience of ill-health are largely considered irrelevant. Genetics and risk discourses thus give medicine power over women's bodies because risk comes to be located in the woman's body and able to be modified primarily through interventions on the body (Lim, 2011; Robertson, 2000). Such a critique does not deny some women are at increased risk of developing ovarian/breast cancer and that RRS can reduce this risk, rather the ways in which genetic and medical discourses represent women's bodies in ways which make them more accessible to medicine and medical interventions is problematised (Happe, 2006).

A feminist analysis suggests genetic medicine is particularly oppressive to women at risk of breast/ovarian cancer since women are disproportionately targeted because women bear offspring. Although offspring receive half of their DNA from each parent and men also carry and pass on BRCA1/2 mutations, the burden of genetic responsibility falls primarily to women (D'Agincourt-Canning, 2001; Nycum, Avard & Knoppers, 2009). Genetic information pathologises women's breasts and ovaries in the absence of disease and expands medicine's jurisdiction over women's bodies (Finkler, 2000, 2003; Happe, 2006). Genes become a tool of female oppression because genes decide who has children, who gets surgery and perhaps even who gets married, creating an "enslavement to risk" (Samerski, 2006, p. 206) which calls upon women to become risk managers of their lives and the lives of others.

To sum, a feminist perspective contends medicine is a site of power where freedom has been historically denied to women. However a critique using feminist literary theory highlights not only is power in medicine potentially an oppressive force, it also acts as a potential form of empowerment (Allen, 2014; A. King, 2004) through the possibility of resistance to power. The next section discusses the feminist concept of resistance further. In this study, feminist resistance was a means of interpreting high risk women's decisions to say no to RRS by problematising the competing and conflicting discourses which surround and permeate HBOC and its management.

Feminist concept of resistance

A central tenet underpinning feminist literary theory is forms of domination and power which subordinate women must be challenged to give women more control over their everyday lives (Easton, 1996; Tyson, 2015). Although the concept of power per se is not always articulated in feminist critique, it is none-the-less critiqued in three key ways: as a form of domination, as a resource to be (re)distributed and as a form of empowerment (Allen, 2011).

A wide variety of feminist perspectives on power exist. For example, socialist feminists support traditional Marxist accounts of power in so much as power is understood as a form of domination grounded in class inequality and economic essentialism (McAfee, 2014). However, Marx's concept of power is criticised for being gender-blind and for failing to take account of women's unpaid and reproductive labour (Allen, 2011). Allen (2011) further explained post-structuralist feminist approaches favour an interpretation of Foucault's concept of power because it illuminates an understanding of the conflict and contradiction in everyday discourses which provide women with the potential for resistance to dominating forms of power. Although some feminists have criticised Foucault's work for being largely gender-neutral (A. King, 2004), a convergence between Foucault and Feminism is

acknowledgement of the body as a site of power relations and both underscore the importance of discourse in creating hegemonic practices and power relations which normalise and control (Armstrong, 2005). A. King (2004) argued the female body was a particular target of disciplinary power and that femininity was a discipline which produced bodies and hence was a means of controlling women. A feminist critique therefore extends Foucault's work on power relations to create meaning of the nature and cause of female subordination (Wylie et al., 2012).

Foucault (1980) claimed the potential for resistance to power existed wherever there was normalisation and domination. In relation to this study, it was purported that dominant discourses permit and support practices of normalisation in relation to what is considered worthy attributes in women including stereotypes of femininity, sexuality and notions of the selfless woman who does *whatever it takes* to stay healthy. It was the very nature of these competing and, at times, conflicting discourses which allowed the female body at risk of cancer to be understood as a site of contested control. In keeping with Foucauldian theorising, a feminist critique of power supported the notion where power exists, so too does resistance. Influential feminist writer Judith Butler summarised this notion: "(...) the subject is neither fully determined by power nor fully determining of power, [but significantly and partially both] (...)" (1997, p. 17). Thus power is wielded on but also wielded by people, giving scope for resistance and redistribution of power. Saying no to RRS was able to be understood as an expression of resistance to power relations which potentially denied women a voice and instead provided scope for a woman's personal aspirations to be heard.

Gotfrit's (1991) seminal work "Women Dancing Back" progressed a feminist concept of resistance through fighting back against forms of female subordination. Gotfrit's (1991) work was an exploration of sexuality and the female body in relation to nightclub dancing practices. The rituals associated with women dancing in nightclubs

and the accompanying female/male expectations and behaviours illuminated an understanding of how women can both reproduce and resist dominant ideologies and discourses in Western society. Although an exploration of resistance through dancing, Gotfrit's (1991) analysis exposed ways in which oppressive stereotypes of femininity and sexuality were developed, tolerated and even came to be expected in Western society.

Gotfrit (1991) argued sexuality and women's bodies were sites upon which the social regulation of women in contemporary culture took place. Within this framework, the construction of the female breast as a potent signifier of femininity/sexuality comes to be understood as an ideology which attached a particular social meaning to women's breasts and bodies. However, forces of social regulation are many and often contradictory hence women's bodies were a site for both oppression and potential empowerment.

In Gotfrit's (1991) analysis, dominant ideologies about female breasts and bodies were both resisted and reproduced by women through ways in which their bodies were presented to or concealed from the male gaze. In relation to breast cancer, a discourse of concealment (Wilkinson, 2001) exists which requires women to hide the physical signs of breast loss (O'Neill, 2013; Rubin & Tanenbaum, 2011). Concealment through prosthesis use or reconstruction is the assumed routine response to breast loss (Cobb & Starr, 2012; Cromptoets, 2012) and from a feminist perspective reflects the importance placed on meeting the male gaze which serves to disempower women facing breast loss (Collie & Long, 2005). Points of resistance emerge from the conflict and contradictions permeated by and through competing dominant discourses. For example, owning a BRCA1/2 mutation and accepting RRS to save life is juxtaposed with dominant ideologies of sexuality and femininity which require women to have two breasts and ovaries. Saying no to RRS is understandable

within the discourse of femininity yet it is a decision which is 'anti-health' in the discourse of medicine.

A final point from Gotfrit's (1991) work is that resistance is more than the nebulous rejection of imposed regulation and normative practices. Resistance is a specific action which challenges underlying institutions and power relations which support the subordination of women. Under any paradigm there will be non-compliers and those who reject the dominant way of thinking. It was resistance to the severely debilitating Halsted radical mastectomy which paved the way for less mutilating alternatives in treating breast cancer (Lerner, 2000). Resistance is thus understood as a means of empowerment and a practice through which women come to be aware of the conflict and contradictions in everyday discourses and seek to create alternate discourses and meanings which make sense of their experiences.

In this study, analysis of women's experiences of owning a BRCA1/2 mutation and saying no to RRS challenged taken-for-granted assumptions about how people respond to cancer risk in Western society. Medical discourse with its emphasis on genetic faults and risk estimates for breast/ovarian cancer fails to acknowledge the social, personal and political components of risk and of HBOC and consequently, accompanying discourses are bound to conflict with women's lived experiences of living with cancer risk. In this respect, medicine was unable to articulate the truths women come to know as a result of their personal experiences, lived in the social reality of multiple, competing discourses.

An examination of resistance thus offered possibilities for understanding the experiences of high risk women and the meanings attached to saying no to RRS. Within medical discourse, genetic information aimed at high risk women which assumes universal responses and actions in response to cancer risk creates the

conditions for the construction alternate discourses which do not marginalise or isolate women who say no to RRS. The feminist concept of resistance hence connected the stories of high risk women who say no to RRS to the communal folklore and signified the emergence of private folklore to make meaning of experience.

In summary then, utilising feminist literary theory in this study allowed an examination of ways in which the female role and femininity are constructed in Western society and how social constructions of breast/ovarian cancer lead to conflict between socially imposed themes and the participants' personal meanings. Reading the personal experience narratives through the lens of feminist literary theory allowed expression of issues important to the participants which medical discourse has not recognised. A feminist stance identified the challenges faced by high risk women arose at least in part as a result of the status imposed on female breasts, and to lesser extent ovaries, in Western society. Application of the concept of resistance created new ways of understanding high risk women's decisions to say no to RRS. While many women undertake RRS and find the experience positive and empowering, some do not: these are the stories of the women in this study.

To an extent, this section unites themes presented in the previous two analytic sections. Consequently, the convergence between feminist, Foucauldian and Marxist theorising is acknowledged. Reasons for this are threefold. First, all three literary critiques provide as Dolby-Stahl (1985, 1989) argued, a means to critically deconstruct the personal experience narratives of high risk women in order to expose themes, attitudes and allusions reflective of societal expectations which influenced how the women's lives are lived and experienced. Second, all highlight power and its unequal distribution in society as a result of seemingly rational or natural 'givens' which structure everyday life. Finally, feminist, Foucauldian and Marxist positions all recognise the body as a site of power relations in Western society and contend power

is something which is both exercised upon and able to be exercised by high risk women thereby revealing the possibility for resistance to power relations.

Step 8: Acknowledging that the researcher creates the document that is interpreted.

The overall aim of this study was to capture the meanings the participants attributed to their lives in written texts (Denzin, 1989). The personal experience narratives of the participants were constructed from one version of potentially many stories which could have been told. Rather than seeking to uncover true and false stories, the biographical researcher's task is to understand *the* story constructed, as stories are always influenced by wider social, cultural and historical contexts which influence and determine standards of truth in particular groups and societies (Denzin, 1989).

The participants' personal experience narratives were "structures of representation" (Denzin, 1989, p. 8) which provided the study data for analysis and interpretation. Stories are told and heard in groups and societies therefore the telling, hearing and interpretation of stories will always be subjective and influenced by an individual's personal values, beliefs and experiences (Frank, 1995). In biographical research, the researcher creates the life which is written about in the same way the teller creates the story which was told thus the subject is created in the text written (Denzin, 1989). In this study, this subjectivity is viewed as a privilege rather than a restriction since the focus is on creating a shared understanding of the phenomenon under investigation. As discussed in Chapter 3, a preoccupation with validity, reliability and generalisability is set aside in favour of a concern for meaning and interpretation (Denzin, 1989; Dolby-Stahl, 1985) and presenting a credible, believable account.

The personal experience narratives of the participants in this study demonstrated an attempt to document reality (Dolby-Stahl, 1985). Whilst the researcher used literary

theory to develop an understanding of the experiences contained within the personal experience narratives, the interpretation was from the researcher's perspective (Hendricks, 1999; Williams & Holmes, 2005) and was therefore individual. It was therefore essential the researcher took full responsibility for the act of interpreting and translating what was heard during the act of storytelling (Dolby-Stahl, 1985). Additionally, since "a life or biography is only ever given in the words that are written about it" (Denzin, 1989, p. 7), the focus of the interpretation was on the *text* of the individual and not the individual as such. The researcher acknowledged each personal experience represented the words of the woman not their underlying philosophy or stable identity (Dolby-Stahl, 1985) as these can never be known. By accepting responsibility for the interpreted document, the researcher absolved the participant from any 'blame' should any discomforting information emerge during the research process (Dolby-Stahl, 1985). Similarly, the researcher's primary obligation was to the people under study hence the promise of privacy was afforded to those who shared their stories and permitted an insight into their most personal experiences (Denzin, 1989). The researcher acknowledged she created the document which was interpreted and therefore provided a reliable method which safeguarded the psychological privacy of the study participants (Dolby-Stahl, 1985).

In summary, the approach taken in this study blended Denzin's (1989) interpretive biography with Dolby-Stahl's (1985) literary folkloristic methodology to unravel and interpret the personal experience narratives of high risk women who said no to RRS within the framework of Western medical discourse and made possible the discovery of the private folklore of this group of women. The chapter to follow comprises the analysis and discussion chapter. The participants' stories are interpreted through the lenses of Marxist, Foucauldian and Feminist literary theories. In particular, the Marxist concepts of ideology and commodification, Foucault's theories on discourse and power, and the feminist concept of resistance are used to focus on the aspects of

experience considered most important: the participants' experiences of being identified as owning a BRCA1/2 mutation which predisposes cancer development, and how these experiences led to the decision to say no to RRS.

CHAPTER 5: THE STORIES OF SUSAN, ANN, PAULINE, ROSIE, MARY AND JACQUI

This section introduces the study participants and describes how intimacy was established with each participant to facilitate the uncovering of meaningful experiences, epiphanies and private folklore. Following this, the participants' biographical timelines with family histories and epiphany moments are presented. The participants' names and those of others were changed to protect anonymity.

Establishing intimacy with Susan

Susan was 35 years old, divorced with one daughter (Emma) aged 14 years. She worked as a classroom teaching assistant in a local high school. Susan was first to respond to the newspaper advertisement seeking study participants. When she telephoned, she seemed undecided about participation and asked several questions relating to the purpose of the study and what would happen with the study findings. I briefly explained the study aims and explained my experiences of working with women facing familial cancer had made me aware of the difficulties faced and I was keen to understand these difficulties to better inform support for these women. I reiterated participation was voluntary and she could give it some thought and get back to me if she decided she wished to participate. However, she stated she was keen to talk about her experiences in the hope they might help others and we arranged to carry out the interview the following week at her home.

On arrival at Susan's home, she appeared welcoming but anxious. I complimented her on her home and accepted an offer of coffee. As the coffee was being made, we chatted about my work and I asked her about her work as a classroom assistant at the High School. I explained I had two teenage children myself and joked I did not envy her spending prolonged periods of time with lots of teenagers which she laughingly agreed was challenging at times. Susan then explained she too had a teenage

daughter and being a divorcee, felt guilty she had said no to RRS and worried she would not be around to see her daughter grow up. I acknowledged this must be difficult for her and as a mother myself, I could see where she was coming from. I asked her if she was happy to commence the interview and she stated yes and she was actually looking forward to sharing her thoughts with someone who had some insight into what she had been through and who was not there to question the decision she had made or persuade her otherwise.

Establishing intimacy with Ann

Ann was 47 years old, married with a daughter aged 16 and a son aged 11 years. Ann and her husband Ken had inherited the family business, a bakery, from Ann's father, who had died from prostate cancer, and she fulfilled the role of book-keeper for the business. Ann responded to one of the early newspaper advertisements and appeared keen to participate from the outset. When she initially contacted me, she asked about the background to the newspaper advert, and wondered if the research was to inform the writing of a book. When I briefly explained the study aims, she immediately articulated she was keen to be involved as she felt it was an area of concern for her family and for women generally. I thanked her for responding, briefly outlined the study aims and arranged to carry out the interview five days later in her home.

Ann lived in an affluent area of town and on arrival at her home it was evident family was very important to her. Throughout the hallway and into the sitting area, the walls were adorned with many pictures of her children and other family portraits. I commented on how nice her house was how lovely the pictures looked. She thanked me for the compliment and offered me tea and biscuits, which I kindly accepted. I thanked her again for her willingness to take part in the study and asked if she had any questions or if there was anything she needed me to explain. She stated no but

inquired into my motivations for the research. I explained how my interest in familial breast and ovarian cancer developed when working as a Breast Care Nurse as I had witnessed first-hand the challenges and dilemmas faced by women and their loved ones. I offered my view the management of hereditary breast/ovarian cancer was increasingly the focus of much research and I believed it was important women affected were given the opportunity to contribute to research by telling health care professionals about their experiences.

Ann went on to tell me she had herself been doing her own research about hereditary breast cancer because every day she worried she had made the wrong decision in saying no to RRS. However, she had found newspaper and magazine articles one-sided: their focus tended to be women who had accepted surgery. Similarly, she had joined an online forum but again, almost all other members of the forum felt accepting surgery was the best option. I said I would be interested to hear more on her thoughts about this and asked permission to commence the interview to which she agreed, thanking me for the opportunity to tell her story.

Establishing intimacy with Pauline

Pauline was aged 33 and lived with John, her partner of 12 years, and her two children: Ross aged 9 and Eva aged 6. She was the youngest participant to respond to the newspaper advertisements and appeared anxious from the outset. When she initially contacted me, Pauline inquired if there was any payment for taking part in the research. I explained there was not and briefly outlined the purpose of the study. She seemed hesitant and said she would give participation some thought and get back to me at a later date. I thanked her for responding and stated I would be happy to answer any questions she had or address any concerns. It was another week before Pauline phoned again saying she was willing to be interviewed. Pauline did not want

me to come to her home therefore the interview was arranged for the following week and took place in a private room I reserved at the local library.

When we met the following week, Pauline remained anxious about participation. I suggested we had a coffee in the library café beforehand to allow her to have her concerns addressed prior to the interview. Over coffee, she explained to me she was nervous about saying the wrong thing and although she felt she wanted to talk about her experiences, she wasn't sure she would be able to answer all my questions or if her answers would be the 'right' answers. I described the study aims in a little more detail and explained it was her story and experiences I was interested in hearing about therefore there were no 'right or wrong' answers. She asked me why I was interested in her situation and I explained my clinical background and work as a Breast Care Nurse and my interest in women's health and cancer genetics generally. Pauline asked if I had children and I told her I had a son of 14 and a daughter of 11. She then told me she also had a son and daughter, and we discussed our children and shared anecdotes for a short while. Pauline was quite animated when talking about her children and she appeared more relaxed. I then asked if she would be happy to carry out the interview, to which she responded yes, and we finished our coffees and headed to the reserved room.

Establishing intimacy with Rosie

Rosie was 39 years old, married to Tom with a son aged 14 called Neil. When Rosie initially contacted me, she seemed anxious and asked several questions regarding the purpose of the study and what participation involved. I explained my interest in the subject matter and what I hoped to achieve by doing the research. Although she stated she would be willing to discuss her experiences, she was concerned her family would find out as she did not want them to know. I explained protecting participants' privacy was an important issue in the study and any information she gave would be

anonymised and at no time would her identity be revealed. I also explained the interview could take place somewhere other than her home but stressed participation was voluntary and she could withdraw from the study at any time. In view of her anxiety, I suggested she think further about participation and call me back if she was certain she wished to take part. She agreed to do so and called me back the following day, stating she wanted to take part as she believed her experiences to be important and she felt people should know about the difficulties surrounding genetic testing. Owing to Rosie's request to keep participation private from her family, we arranged to carry out the interview at the home of a friend (Jane).

When we met at Jane's house on the day of interview, Rosie was friendly but still appeared anxious. Jane was present while we had coffee and Rosie explained her friend had been a source of support and comfort during her experience whereas she had felt unsupported by her family and hence had not wished the family to know of her participation. Rosie again asked about my motivation for undertaking the research and I explained familial cancer was an area I had always been interested in since my time working as a Breast Care Nurse because I had cared for women facing difficult decisions about familial breast and ovarian cancer. I also explained my interest in women's health generally, both as a woman and a researcher, and my view health care professionals needed to know more about the experiences of women in breast/ovarian cancer families. Her friend Jane agreed this was important and my research sounded very useful. I again thanked Rosie for her participation and offered I would be interested to hear more about her experiences. At this point, Rosie's friend Jane excused herself and the interview began.

Establishing intimacy with Mary

Mary was 37 years old and married to Robert. She had two daughters aged 21 and 16 years. Her oldest daughter lived with her partner and had a child of 3 months

whilst her youngest daughter lived at home. Mary was a member of the same online support group as Ann and contacted me after discussing the study with her. Like Ann, Mary had found herself in the minority with regards to saying no to RRS, as most members of the support group were planning or had undergone surgery.

When Mary first contacted me, she explained Ann had discussed taking part in the study with her. She stated she thought my study sounded very interesting and she felt it was important people understood how difficult the genetic testing process was and decision making around RRS was not easy. I thanked her for her interest and explained I would need to tell her more about the study and give her some time to carefully consider participation. I explained the study aims, what I hoped to achieve by undertaking the study, what she would be required to do and she stated she would consider taking part. She called back a few days later and we arranged to carry out the interview at her home the following week.

Mary was friendly and welcoming when I arrived at her home. We spent some time chatting and having tea and biscuits. I had previously discussed my nursing background with Mary when I was explaining my interest in women's health and familial breast cancer. Mary talked about her work as a care assistant in an elderly care home and how much she enjoyed the role. She explained she had fallen pregnant at an early age (16) and had therefore left school without completing her education. This was of some regret as she had always wanted to become a nurse but had been unable to do so. We talked about nursing and health care generally, and the many changes which had taken place in our lifetime. This led on to a discussion about cancer and genetics and Mary talked about how different health care had been when her mother had first been diagnosed with and treated for breast cancer. I then suggested we commence the interview and Mary agreed.

Establishing intimacy with Jacqui

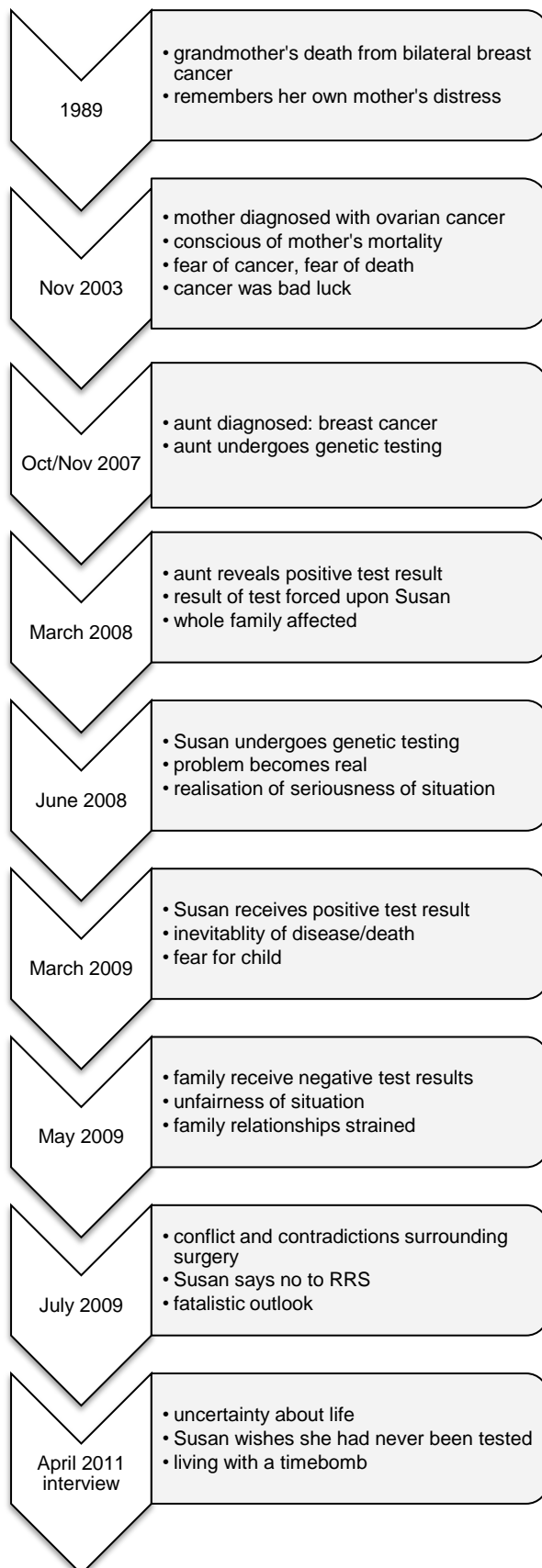
Jacqui was 40 years old, married to Paul with two children: a daughter aged 17 and a son aged 15. Her son had mild autism but attended main stream school and appeared to be doing well. Jacqui was the final participant to be recruited following one of the later newspaper advertisements. She had not seen the newspaper advert herself but a relative had pointed it out to her. When Jacqui contacted me, she was bright and cheerful and keen to find out more about the study. I explained the study aims and what I hoped to achieve by doing the research and encouraged her to ask questions if there was anything she was unsure of. She said she had no questions but was very interested in telling her story as she believed her experiences could help other women in a similar position. I thanked her for her interest and explained what would be required of her. Since she lived some distance away, we agreed to meet for the interview four weeks later to allow me time to plan travel arrangements. I advised her should any questions arise during this time, she could call me for clarification. I also asked her permission to call her the day before the interview was scheduled to confirm she still wanted to participate, prior to me travelling to her home town. She happily agreed to this and I once again thanked her for her willingness to take part and stated I looked forward to hearing her story when we met.

Jacqui was friendly and welcoming when I arrived at her home to carry out the interview. As she made coffee, she enquired about my train journey and asked me a little about where I lived as it was a part of the country she had never been to. I briefly described my home town and explained I had visited the town she lived in as a child as it had been a popular seaside holiday destination when I was growing up. Jacqui was younger than me but remembered being a child and the many tourists who came to the town, commenting the numbers had declined over recent years. We talked a little about how things changed generally and how different things were for children growing up now. Jacqui informed me she had two children aged 17 and 15 years and

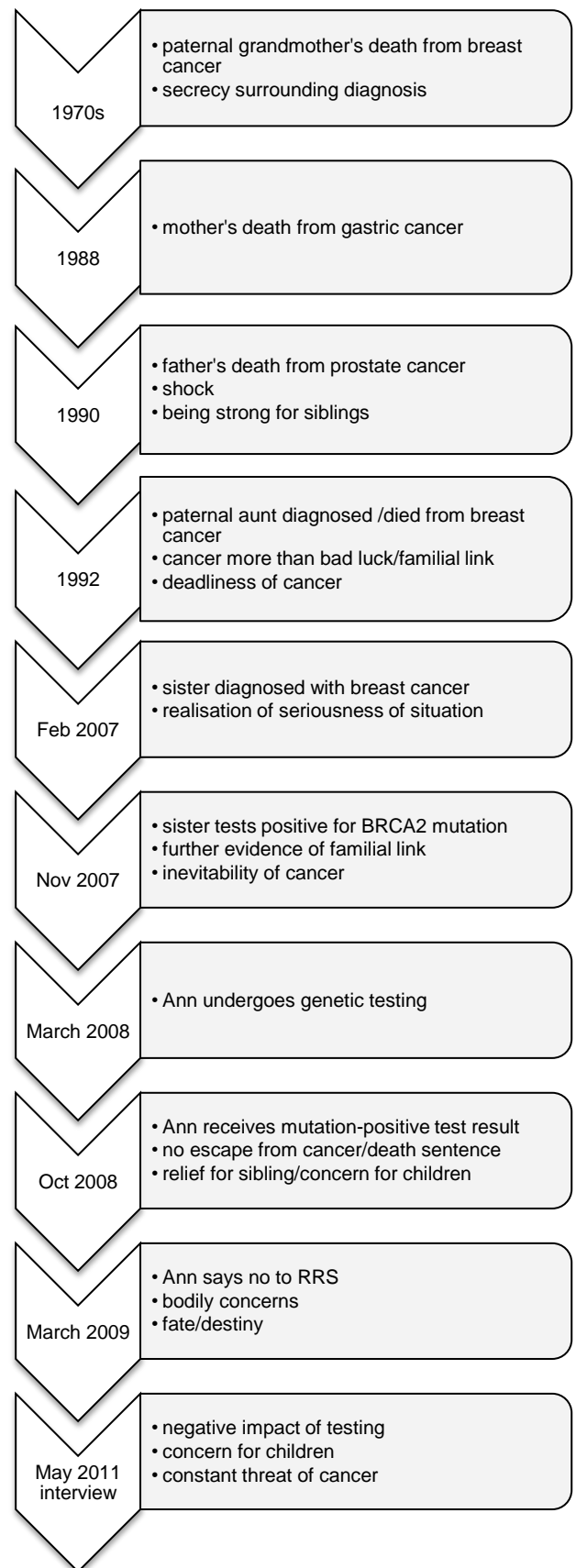
stated she worried about the world they were growing up in, especially her son with his autism. I offered I was also a mother of two and agreed how challenging bringing up children could be at times. Jacqui then talked about her additional worries about her children as a result of her cancer family history. I acknowledged her worries and asked if she felt comfortable to commence the interview. She re-iterated she was keen to tell her story and the interview began.

In keeping with Denzin's (1989) approach, the participants' biographical timelines are diagrammatically presented next. These represent the life trajectories of the participants in relation to their family histories and turning point moments up until the time of interview.

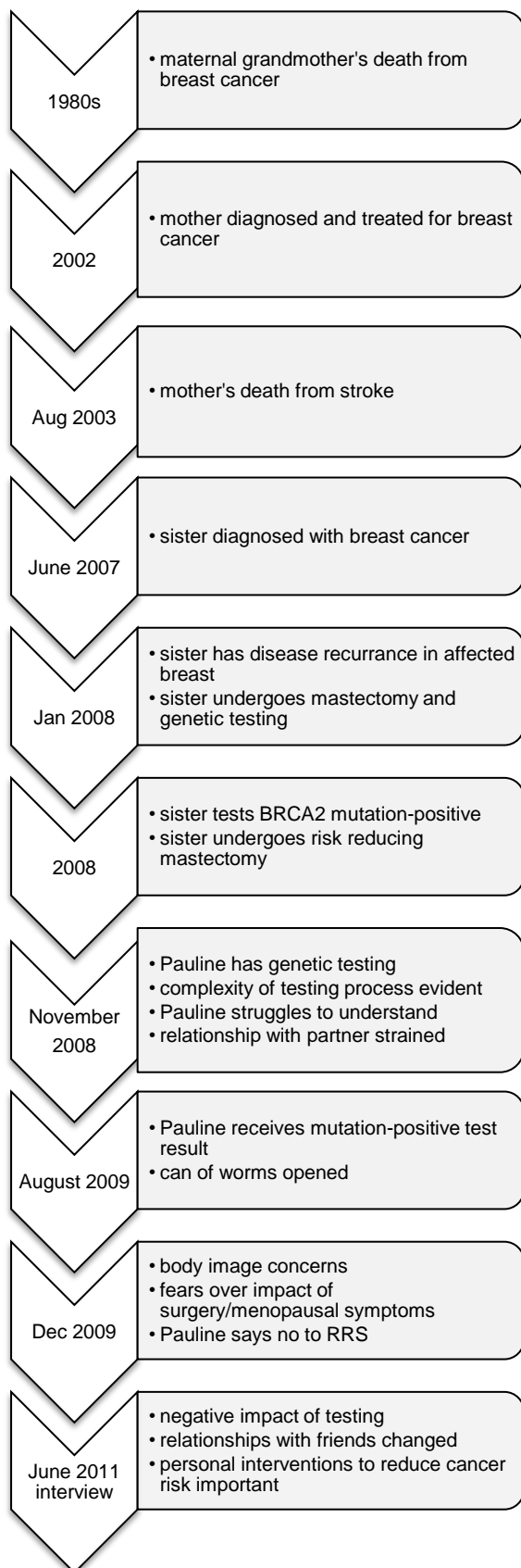
Susan's biographical timeline



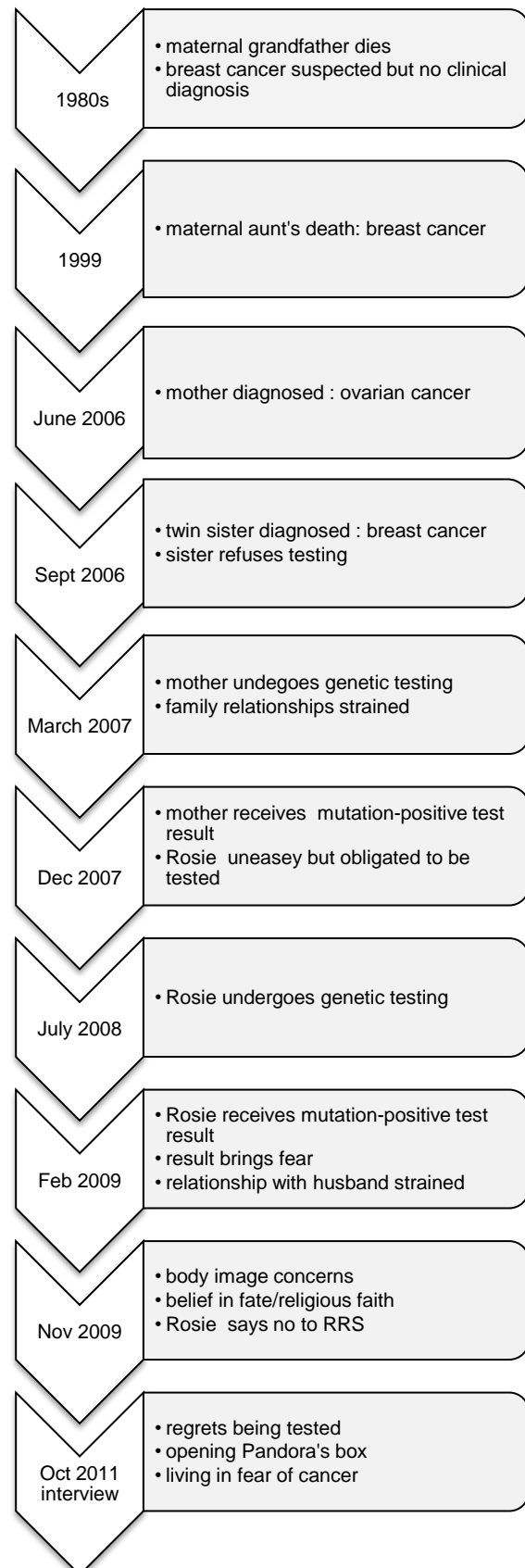
Ann's biographical timeline



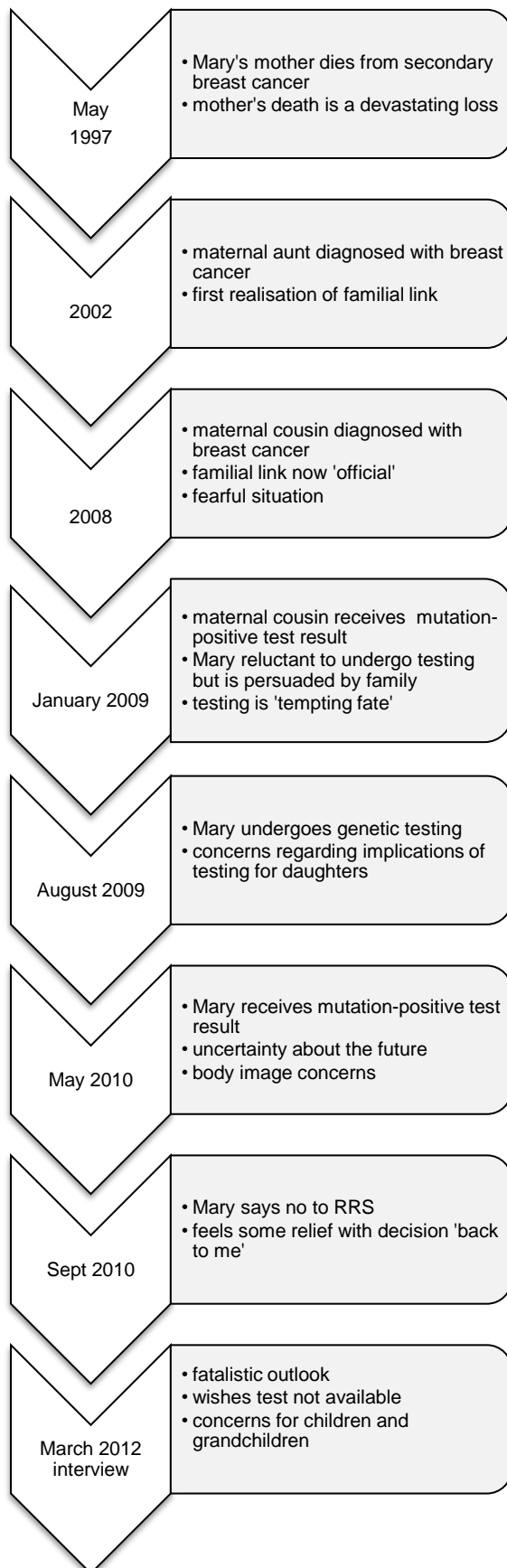
Pauline's biographical timeline



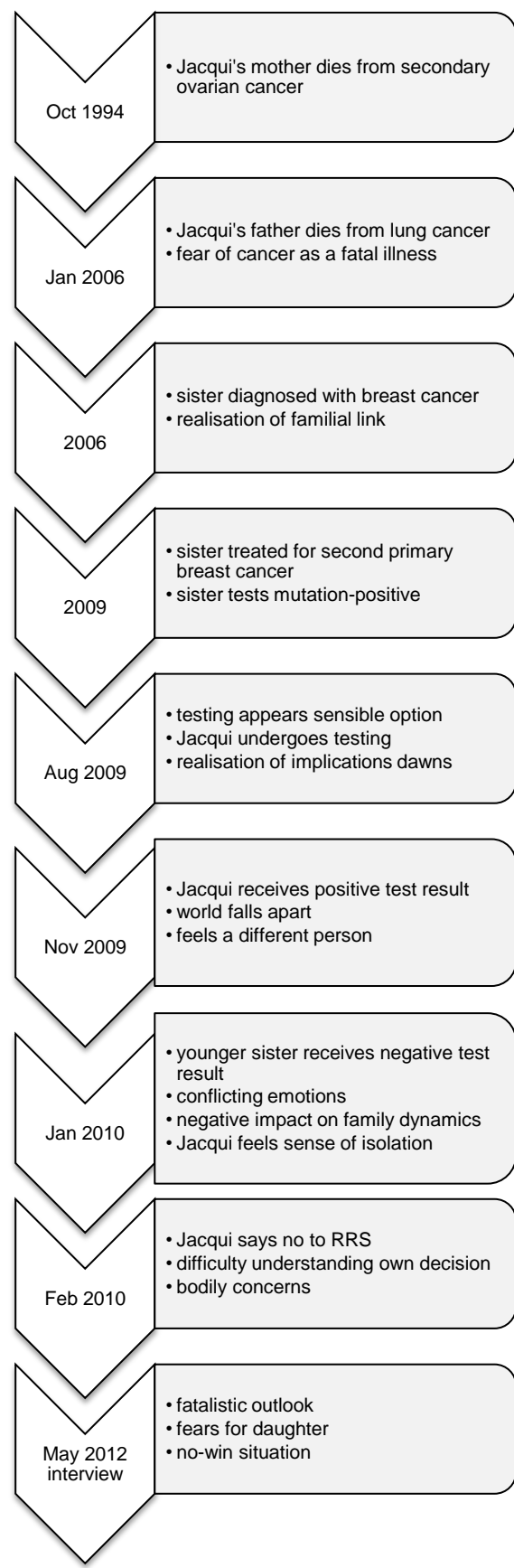
Rosie's biographical timeline



Mary's biographical timeline



Jacqui's biographical timeline



CHAPTER 6: ANALYSIS AND DISCUSSION

Introduction

The previous chapters justified the approach taken in this study and presented a detailed description of the method used to gather the data. This chapter provides an analysis of the data based on the biographical method. The analysis is written around what Denzin (1989) referred to as epiphanies or turning point moments and what Dolby-Stahl (1985) referred to as themes. The most significant epiphany was testing positive for a BRCA1/2 mutation. The analysis here stems from this and incorporates other epiphany moments as outlined in the participants' biographical timelines. The following sections analyse, interpret and discuss these biographical events as captured in the participants' texts in relation to the three identified literary theories. While Dolby-Stahl (1985) uses the term 'narrative' and Denzin (1989) uses 'personal experience narrative', the remaining thesis will refer to the participants' stories.

This study utilised Riessman's (2001, 2006, 2008) thematic analysis as the underpinning framework for analysis of the participants' stories. The stories have been "cleaned up" (Riessman, 2008, p. 57) to remove the researcher's utterances, dysfluencies in speech and generally edited to make the excerpts more readable and to ensure the passages presented are contextualised in relation to the issues of concern. Ellipses (...) are used to indicate omitted words such as repetition and false starts. Clarification of meaning and explanations of local dialect and vernacular are provided in square brackets where necessary. The names of the participants and other individuals referred to have been changed to protect anonymity.

An interpretation through the lens of Marxist Literary Theory

This study explored women's experiences of being identified as high risk of developing breast/ovarian cancer and saying no to RRS. Women's breasts and ovaries carry distinctive social and cultural meanings in Western society therefore surgery to remove

them, particularly in the absence of disease, presented participants with a dilemma. Understanding a woman's choice to say no to the removal of healthy breasts/ovaries required their decision to be considered within social, cultural and historical world views which allowed interpretation of their experience. This chapter applies a Marxist view which contends Western society is a capitalist society in which dominant ideologies shape human experience in relation to gender, sexuality, work, the family and other cultural ideals (Denzin, 1990).

The analysis and discussion to follow drew on two important and interlinked concepts in Marxist literary critique. That is, ideology and commodification. Both Marxist conceptual tools were useful for deconstructing participants' experiences. Ideology influences beliefs and perceptions in daily life and forms the basis of understanding reality. Ideology also promotes commodification of gender, sexuality and the breast presenting each as an essential and natural component of social life and allows the commercial exploitation of HBOC. Commodification is the process, whereby, people and the products of labour are transformed into objects considered useful and/or which have exchange value (Lock & Nguyen, 2010). A Marxist interpretation exposed ideological conflict and contradiction in relation to HBOC and how these confirmed or undermined the decision to say no to RRS, creating ambivalent experiences for the participants and providing scope for the creation of personal ideologies which resisted the dominant, externally imposed ideological forces.

Gene mutations as cancer genes

A recurrent and striking feature of the participants' stories was the continual referral to BRCA1/2 mutations as 'cancer genes'. Every participant referred, in some way, to having 'the' or 'a' cancer gene and argued this ownership in terms of something found in their body, but not in the bodies of other women.

Susan explained how her family first became aware of the presence of hereditary cancer as a result of her affected aunt's mutation-positive genetic test result:

We found out about the gene only after Auntie Helen got her testing done (...) when she was in hospital getting chemotherapy. They said she could get tested to see if she had a breast cancer gene which could maybe be passed down the family.

Susan's family were unaware her aunt was being tested until her aunt revealed the test result during a family meet-up, which had led to some disquiet at the time:

So it kicked off a bit when we got there [during a visit to her Aunt's home] and she says she's got something to tell us and then just comes out with it, saying she's had this test and she's got a cancer gene and we've all to see a specialist [be]cause we might have it too. This was in front of Emma [Susan's daughter] too. She didn't give us the chance to say "right, get the weans [children] out the room while we talk about this". It was really just sprung on us (...) we weren't given any option to not hear about it.

Prior to testing, Mary had hoped she would not have "the gene" and Jacqui admitted being afraid because she had "inherited the cancer gene" which might shorten her life. Ann also believed she owned a cancer-causing gene which could be passed on to her children and discussed her fears this might be the case:

Sometimes I look at her and her friends, all young and full of life and vitality and all so beautiful, then it pops in my head she might be carrying the gene and have her life turned upside down. I feel so guilty sometimes when I think I might have passed it on to her.

There appeared to be a perception only high risk women carried BRCA genes, despite these genes being part of every human's genetic makeup, passed on to all offspring (Arden-Jones et al., 2008). No participant differentiated between the gene itself and inherited mutations which are associated with cancer development (Rosenthal et al., 2012). Instead, there was a belief people either had a cancer-causing gene or not, as illustrated by Rosie who explained her position of risk of cancer in such terms:

But when they actually found the gene in me, they knew my risk was much much higher than it would be normally, if I didn't have the gene. I am higher than her [sister] because I've got the gene and she doesn't.

Similarly, although Ann understood most women who develop breast/ovarian cancer do not have an inherited gene mutation (NICE, 2013), this was expressed in relation to

having the gene or not rather than having a mutation or not. Ann explained: “more women without the gene get cancer than those with it”. These statements typified how the language used to discuss gene mutations created an understanding breast/ovarian cancer was primarily caused by genes found *only* in high risk women; an erroneous belief which is not in keeping with most cancer development.

BRCA1 and BRCA2 are genes located on chromosomes 17 and 13 respectively and are found in all human DNA (Yoshida & Miki, 2004), therefore in every person. Certain deleterious mutations in these genes are associated with an increased risk of developing breast/ovarian cancer, hence the labelling of the genes as BRCA1 (**breast cancer** susceptibility gene 1) and BRCA2 (**breast cancer** susceptibility gene 2), (Lodder et al., 2002). Whilst one may reasonably argue this represents no more than a shorthand way of referring to mutations on chromosomes which predispose breast/ovarian cancer, a Marxist interpretation suggests that the labelling of the gene faults as ‘BRCA1 and 2 genes’ can be understood as an ideological practice which proposes medicine has discovered why women develop breast/ovarian cancer and belies the reality of limited medical knowledge.

More than 1000 different mutations in these genes have been identified (Antoniou & Easton, 2006) and much fewer are known to be deleterious (Antoniou et al., 2003). Current evidence suggests BRCA1/2 mutations account for at most 10% of all breast cancers and 15% of all ovarian cancers (NCI, 2014). Scientific understanding of the genetics of hereditary breast/ovarian cancer predisposition remains largely unexplained (Snape, et al., 2012; Tamir, 2010) and further research is needed to understand the clinical implications of different gene mutations (Kurian, Sigal & Plevritis, 2010). As Werner-Lin (2008, p. 114) pointed out, “genetic testing for HBOC is predictive, not prophetic” because science is not able to say who will develop cancer and who will not. The vast majority of breast/ovarian cancers occur for reasons other than BRCA1/2

mutations, yet these genes are continually referred to as 'the breast cancer genes' in professional journals, the media and cancer charity literature. Only on one occasion was there acknowledgement of an inherited mutation in the BRCA1/2 gene as being the cause of increased risk when Mary said:

(...) they [genetics staff] said with the gene fault the risk of cancer is really high. They can't always tell for everyone and it depends on what one [mutation] you've got, what the actual risk will be but they do know there is a risk. They told us the gene fault I had meant my risk of getting cancer was 80%.

Interestingly, Mary's cognisance of a mutation rather than the gene itself as being responsible for increased risk was couched within her discussion of how her risk status was communicated by the geneticist: Mary herself referred to "the cancer gene" when presenting her personal perceptions of risk:

When you first find out you've got the cancer gene, it takes a while to sink in, even though I was half expecting to have it with my family's history, I thought it would be the case we had a cancer gene in our family but it still took a while to accept. I think maybe the shutters just come down, like a survival instinct. I was really emotional for a while (...) angry because I had the gene and my risk being so high because of it.

Consequently, the participants' stories revealed a 'reality' about hereditary breast/ovarian cancer has been perpetuated through the ideological use of language and the labelling of gene faults as 'cancer genes'. Such an ideology suggests some people carry a cancer-causing gene whereas others do not, which explains 'who gets cancer'.

Interpreting the participants' experiences through the lens of Marxist Literary Theory (MLT) revealed the labelling of gene mutations as 'cancer genes' commodified risk and allowed gene faults to be constructed as a form of biocapital (Franklin & Lock, 2003; Rose, 2007). Biocapital refers to the use of living organisms or life forms to generate income and occurs when biotechnology becomes primarily a source of market value (Rajan, 2006). Helmreich (2008) argued advancements in biotechnology allow biological materials including human genomes to be increasingly capitalised upon and

used to underpin projects aimed at profit generation. Life and life forms including genes as biocapital thus become objects of exchange in the capitalist system and a significant resource for the joint generation of health and wealth (Acero, 2012).

The construction of BRCA mutations as biocapital is exemplified by the patenting of the BRCA1 and BRCA2 genes by Myriad Genetics in 2001. Myriad was able to secure a monopoly of rights to genetic testing and therapeutic uses of BRCA1/2 genes which gave power over the use of the genes and exclusive rights to commercial exploitation (Hanson, 2002), generating billions of dollars of profit for corporate interests (Thomas-Pollei, 2008).

The labelling of particular gene faults as 'cancer genes' also supports what Birch (2007, p. 85) referred to as a "logic of morbidity" which allowed medicine and science to create economic yield. It is the creation of new morbidities, in this case 'cancer genes' which generate economic opportunity and allow economic value to be attached to risk reducing interventions (Birch & Tyfield, 2013). Gene faults essentially allow a diagnosis of risk to be made which in turn permits the production of new drugs, technologies and professional services and thus new markets for these services (Löwy, 2010).

Moreover, the material embodiment of risk as residing in one's 'cancer genes' means people become indistinguishable from their genetic code, since genes are culturally associated with the essence of life (Thomas-Pollei, 2008). If one is identified as owning a 'cancer gene', other causes of cancer external to the body are discounted or relegated; and, genetic causes of disease take centre stage. This in turn creates and sustains market demand for expensive genetic technologies to diagnose and manage cancer risk. Jacqui revealed how her new-found genetic knowledge caused her to call into question why people develop cancer:

When you think of all the cancer in the family, well its common sense really isn't it? I mean, my mother and father both smoked and they both got cancer. He [father] got lung cancer and her, it was ovarian. Smoking and cancer, well that's been known for ages but you think now maybe, is it smoking? Maybe he [father] had something [genetic] too (...) maybe that's why people who don't smoke like Beth [sister] still get cancer and how lots of heavy smokers seem to be okay.

Jacqui questioned smoking as a cause of cancer, and instead identified genetic causes as being "common sense". This reflects the findings of Finkler (2000) who also found people stated it was 'common sense' that cancer was a result of genetics. Likewise, the other participants and their families almost entirely attributed cancer to the singular cause of 'the cancer gene(s)'. This reductionism represents an "ideology of genetic essentialism" (Finkler, 2000, p. 2) whereby cancer becomes a product of genes, ensuring women without disease are dependent upon medical expertise to reduce risk and stay healthy. Owning a BRCA1/2 mutation thus comes to be understood as a threat to life, as explained by Susan:

I mean I was pleased for her, really I was honestly, but it wasn't fair because she [(sister)] had been the one really trying to get me to go, to persuade me saying we all need it done, then she's escaped and I'm left knowing I could have this thing that could kill me. And she's not even got any kids. God you must think I'm horrible, but I just felt really hard done to I suppose, why me, and worried about Emma (...) I mean, no one wants to be faced with what might kill them.

Here Susan's story shows how she interpreted her genetic status as a threat to life, referring to it twice as something which could kill her, equating her cancer risk with her mortality. This happens in part owing to the cultural significance of the word 'cancer' and a collective worry about cancer. Susan said:

So she was okay but it hit me hard (...) when you see your mum in hospital with all the tubes and stuff and more so when you hear the 'c' word [cancer]. I am thinking "okay so they say she's been lucky, but I mean *its cancer*" [said with emphasis].

Susan's response to her mother's diagnosis reflects the fear of cancer which is almost unrivalled (Clarke & Everest, 2006; Harrington, 2012; Vrinten et al., 2014) because cancer ideologies ensure society takes for granted cancer is deadly and the ultimate threat to life, a risk to be removed at all costs. A MLT lens proposes that the word

'cancer' is a potent ideological tool, and the risk of carrying BRCA1/2 gene mutations creates the need for an industry to manage the risk through genetic testing and maintains medical power as the overseer of these tests. Cancer risk, as an ideological tool maintains that those deemed in this category respond in a desired way and that *cancer risk* is communicated and perpetuated in society as intended by key agencies involved in maintaining ideological control of the population. Ann, in particular, frequently referred to "the 'c' word", describing it as "your worst nightmare" and "the one word you never want to hear". Jacqui also alluded to the cultural significance of the word 'cancer' when she explained:

Common sense tells me there's something in every family, you know, something's got to get you (...) but to have cancer in your family, that has to be the worst thing you can have, to be told you are a cancer family. Everyone knows cancer is a killer, even the treatment, the radiation and the chemo[therapy], well they're not pleasant. Beth [sister] had a terrible time with her treatment, it nearly finished her off. So the thing about having cancer in the family is, well it's the issue with the cancer but also the treatment (...) it's like a double whammy if you have cancer.

Similarly, Rosie summarised the fear associated with cancer:

You don't need to be a doctor to know cancer is one of the worst things you can get, especially when it spreads, there's not usually much they can do about it. Plus even having surgery can be risky. Once they open you up, anything that's in there can spread. That's what happened to a woman my sister knew. She went in for surgery on the bowel and then within two months, it had spread to her liver and she was dead (...) but before the operation, the scans were okay, it was the operation, made it spread.

These findings submit that a belief in the presence and destructive power of a cancer-causing gene which serves as an ideological force. A Marxist perspective, therefore, contends 'cancer' is ideologically empowered to mean death. Hence, cancer risk is an ideological tool which creates and sustains fear. However, this is not to deny cancer is a disease which causes significant mortality and morbidity, nor that genetic mutations exist which make cancer more likely. Rather, from a Marxist stance, it is argued that ideologies of fear permeated through cancer and risk discourses exploit the emotions and worries of high risk women and permit ideological control for economic gain.

The creation of BRCA1/2 mutations as ‘cancer genes’ adds to their value as biocapital and effectively places a monetary value on cancer fear. The ideology of fear obscures the vast wealth generated through genetic technologies and what goes unnoticed is that most breast/ovarian cancers occur for reasons other than BRCA 1/2 mutations.

To sum, interpreting the participants’ stories through the lens of MLT submits that the labelling of certain genetic mutations as “the breast cancer genes” is an ideological tool which endows risk with a material reality. The deadliness of cancer generates a level of fear which compels individuals to take steps to stay healthy and simultaneously supports medical intervention for dealing with cancer risk. The next section turns to an analysis of the participants’ stories in relation to ideologies of treatment for risk and ways in which risk was constructed as something which could be dealt with through the consumption of a number of medical technologies. Again, conflicts and contradictions were inherent in the influences of ideologies which diffused uncertainty and both consented and silenced resistance to the dominant medical pathway for HBOC risk.

Ideology, genetic responsibility and consumerism

The stories of Susan, Rosie, Ann, Pauline, Jacqui and Mary revealed the stressful and enduring pressure exerted upon them which obligated them to attend to the threat of cancer. There was strong belief no woman could ignore a family history of breast/ovarian cancer or a mutation-positive test result. Despite current focus on genetic testing as a key step in managing risk of breast/ovarian cancer, analysis of the participants’ stories revealed testing was not always keenly initiated by the participants but rather there was often a degree of ambivalence around testing. Susan described her initial uncertainty about genetic testing thus:

When we were first told we needed testing, I wasn’t really sure I was going to have it done. I’m a bit superstitious really (...) the more you talk about something the more likely it is to happen. But everyone else, they were all like, think about Emma [Susan’s daughter], you need to do it for

her, you need to know if you've got it or not. I don't know, maybe I was just trying to bury my head in the sand.

Mary also stated she was initially cautious about entering the genetic testing process but discussions with others had made it clear knowledge of genetic status was something which could and should not be ignored:

I was never keen for the testing. Angela [Mary's cousin] was keen to have it done because she thought it would help everyone get protected. I think it's different when you've already got cancer, the testing is like finding a reason for it. An explanation of 'this is why I got it' [cancer]. But when you don't have cancer (...) to me it was like tempting fate. Getting it done. But there was a lot of pressure on me, from people who said "how can you not get it done, you need to know, how can you get sorted if you don't know", that kind of thing.

These excerpts show Susan and Mary had initial reservations about genetic testing but were subjected to pressure from others in the family to uncover their genetic status. Lock and Nguyen (2010) argued reluctance to undergo genetic testing is a plausible response in nature of the potential negative consequences of being identified as owning a genetic mutation which predisposes cancer. However, what this study illustrates is ideologies around cancer risk and prevention strategies direct how one should respond to the threat of cancer, namely by submitting to genetic testing. What is omitted from cancer and medical ideologies is the option to avoid knowledge of genetic status by declining genetic testing. As the participants' stories revealed, any reservations an individual might have held regarding testing and finding out one's genetic status were likely to be quickly quietened, even condemned by others, on the basis knowledge of genetic risk is paramount. Ann described how her cousin's refusal to be tested had been met with incredulity by others:

There was a lot of cancer in our family. We were all already worried about it, being in the family. (...). Christine's [sister] test wasn't a surprise, she already had cancer and at a young age. (...) there was an understanding after Christine's diagnosis we would be tested, all of us, because of the history. When my cousin said she wasn't interested, there was (...) a huge intake of breath. (...). I don't think anyone quite believed what she was saying. (...) I have to admit I was at first anyway, shocked. Assumed she would. Of course I see where she's coming from now but at the time, no. I think she was put under the spotlight, "why are you not having it?" Her husband was really off with her, got the kids to speak to her. It was all really unpleasant.

Medicine provides a service to women with a family history of breast/ovarian cancer by offering interventions to diagnose and manage risk. Medical technologies and pharmaceuticals are then able to be consumed by health care professionals and at risk individuals in the quest to modify risk and prevent cancer. Genetic medicine has resulted in a globalised industry which generates substantial profits for pharmaceutical and biomedical technology companies (Baird, 2000; Birch & Tyfield, 2013, Hanson, 2002; Lock & Nguyen, 2010; Zones, 2000). The Human Genome Project is estimated to have cost \$3billion (UK Parliament, 2012) and genetic testing is now a multi-billion dollar industry with spending on genetic testing set to reach \$25 billion dollars in the United States of America by 2020 (United Health Group, 2012). In the UK, more than £5 billion pounds annually has been allocated to genetic science and research programmes as part of what the government describes as a \$100 billion synthetic biology marketplace (UK Parliament, 2012). In Australia, the current spend on human genetics Research and Development is estimated to be in the region of \$795 million dollars per year (The Centre for International Economics, 2013).

A Marxist interpretation contends ideologies about breast and ovarian cancer create fear and fuel demand for genetic testing and risk reducing interventions. High levels of cancer fear are necessary to ensure people, or by proxy the State, are prepared to pay the costs of genetic tests. A key way in which the fears of Susan, Rosie, Ann, Pauline, Jacqui and Mary were exploited through such ideologies related to their concerns for their families, especially children. The participants' stories revealed the obligation to uncover one's genetic status was experienced as an individual's responsibility to themselves and to their families. Pauline explained her sister's first reaction to being confirmed as mutation-positive was to request testing for others in the family:

Because she [Pauline's sister] got tested when she was still getting treated, it didn't seem to take long. We weren't really thinking about the test until it came back and it was positive but it was to be expected really. Her first reaction was for me to get tested. She asked the doctor: "can my wee [younger] sister have it done"? Her first concern was for

me really. We've always been close but after mum died and then she got cancer, well we were even closer as it was just the two of us. They had told her before-hand if she was [mutation] positive, they might be able to test the others in the family if they wanted it (...) to be honest I think that was one of her reasons for getting it done, to see if it would help me find out my risk.

Here, Pauline believed her sister underwent testing in order to help others in the family find out their risk of cancer. Not only does this highlight her sister's obligations to the family, it also appears to have influenced Pauline's decision to have testing:

Of course when it came down to it, of course I would have it done [testing]. I couldn't not have it done could I? What would that say to Sarah [Pauline's sister]? It would have been a right slap in the face after what she'd gone through. And then of course there was Ross and Eva [children] and John [partner] to think about.

Hallowell (1999) and Rowley (2005) reported women undertaking genetic testing for hereditary cancer often did so because of promises made to afflicted relatives which in turn reinforced their obligations to others and influenced their risk management decisions. Pauline exhibited a deep responsibility to her sister and her partner and children to undergo testing. The use of the words 'of course' appears three times in the short excerpt above and reveals a certainty about Pauline's decision to undergo testing, but a certainty brought about through her responsibilities to others rather than personal need to find out. Although Pauline did not explicitly outline her obligations to others, her decision to undergo testing was entirely framed with reference to her sister, partner and family and the refusal of testing was considered almost an abuse of others in the family. Pauline alluded to the possibility of not being tested but ruled this out because of responsibility to her sister who had been treated for cancer. Familial obligations thus emerged as an important motivator for engaging in genetic testing and it was clear such obligations played an initial role in convincing participants to act to attend to cancer risk.

Marxists view the institution of the family is part of society's superstructure and key to maintaining a healthy, productive workforce (Waitzkin 1984, 1989). This lends support

to claims the importance of the family and a woman's role as protector of health is persistently endorsed in Western ideology (Acero, 2012; Lerner, 2000; Warner & Procaccino, 2004). The nature of genetic medicine inevitably implies medicine for the family (Geelen, Hoyweghen & Horstman, 2011; Novas & Rose, 2000) as the whole family is implicated through risk of disease (Kenen, Ardern-Jones & Eeles, 2003). Accordingly, decision-making on risk reducing interventions is argued to be best taken within the context of a family clinic (Zagouri et al., 2013). This has implications for women at risk of HBOC who may be ideologically consigned to making decisions in the best interests of the family. Ann's story also displayed how her fears for her children influenced her decision to find out her genetic status and her subsequent feelings once a gene mutation was identified:

Well as a mother, your first thoughts are always for your family, your children and what it means for them. You need to find out things, you need to know, like, am I going to be around for them? Will they get it? And of course it wasn't just Gillian [daughter] to worry about because it looked like our gene came from my grandmother through my father (...) so Jack [son] was also at risk of cancer, well more at risk than normal, which was really hard to believe at first, men could get breast cancer. I'd never heard of it in men so I didn't really think about Jack until later on when I had more counselling and it came up. So I was really worried for both of them, and how to broach the subject with them.

Like Pauline, Ann framed her decision-making vis-à-vis genetic testing in the context of family responsibilities and explained her decision was influenced by her role as a mother and the need to find out the implications of her genetic status for the sake of her children. Ann's first concerns were not for herself, but for her children; would she still be alive *for them* and would they develop cancer.

The analysis here supports previous work which suggested women at high risk of developing cancer made decisions in response to risk in part due to feelings of responsibility for the health of the family (Bottorff et al., 2002; Bruno et al., 2010; Foster, Watson, Moynihan, Ardern-Jones & Eeles, 2002; Hallowell, 1999, 2000; Hamilton, 2012; Rowley, 2005). Being a parent is reported to be a significant predictive

factor for uptake of RRS (Fang et al., 2005; Karp, Brown, Sullivan & Massie 1999; Meijers-Heijboer, et al., 2000). This is perhaps not surprising when caring for the family is central to the breast cancer discourse (Blackstone, 2004) and the value of female nurturing is promoted and endorsed through medical encounters (Gibbon, 2007). Thus, ideology has the potential to impact women's decision making in ways which put the needs of others first. The family complete with nurturing mother, is key in Western society and is endorsed through medical discourse which situates women as the gatekeepers of family health and guides women to undertake interventions to reduce the threat of cancer. Likewise, a Marxist perspective emphasises that a stable relationship between the family and successful economic production in capitalist societies is crucial; therefore, protection of the female (mother) as homemaker and nurturer is essential to the maintenance of a healthy productive workforce (Althusser, 1971; Waitzkin, 1984).

HBOC is viewed as a threat to economic stability because it threatens the lives of women and their ability to produce and reproduce. Official guidelines on the management of HBOC such as NICE (2013) recommend that women preserve their ovaries until childbearing is complete further endorsing the importance of women's role to reproduce in Western society. Women who say no to genetic testing and risk reducing interventions may be construed as putting not only themselves at risk, but also the entire ideological framework underpinning capitalist society because of the covert linkage between the family and successful economic production (Waitzkin, 1984). The application of MLT, in this study, thus contended that the nature of genetic medicine conveniently strengthened the ideological impact of the family and allowed the transmission of subliminal messages through medical encounters to reinforce dominant social patterns in relation to health behaviours, the family and women's responsibilities to themselves and others. Jacqui said:

When she [sister] got the second breast cancer, she was referred to a bigger hospital and she saw a specialist (...) he was the first to ask about the family's history and bring up the genetics. He said it was important to think about testing because with the situation with my mum and Beth and if it was in the family we would need to think about it because the whole family could be affected. Beth was really poorly at the time but she thought it was something she could do for us.

Given the above, it is not surprising that the analysis of the participants' stories revealed decision-making around genetic testing and RRS were often framed as moral endeavours. Susan, Rosie, Ann, Pauline, Jacqui and Mary were exposed to a barrage of opinions from others and at times felt coerced into action through comments which induced both blame and guilt. Pauline revealed a friend had suggested not having RRS was akin to not loving her family:

Everyone finds it strange I decided not to [have the surgery]. Some people have been right nasty. I had one friend tell me I was selfish. If I loved my family I would have it [surgery] for them (...) quite the expert on what I should and shouldn't be doing. (...) as if I was a bad mother for not [having surgery]. Well she's not a friend anymore! I cut her right out. Others have been more nice about it but I can tell they struggle to understand. It's hard for me to explain to them, they seem to think I'm mad or something.

Ann also explained how friends and family used various techniques to persuade her to undergo RRS and how she struggled to explain her decision to say no to surgery to others:

When I said I wasn't going to have surgery, everyone wanted to know why and they would try and talk me round, tell me it was a no-brainer as it would stop me getting cancer. I even had friends quoting statistics to me (...) it was hard for them to understand as they saw it as the most obvious and sensible thing to do. Even my cousin said I should have it [surgery]. Now that *really* [raised voice] pissed me off because she refused to even be tested! So it felt like a constant battle to try and explain why I didn't want the surgery. I could barely explain it to myself but I just couldn't do it. But there is a lot of pressure, it almost seems like a moral dilemma. People at the end of the day mean well but they don't understand and they don't help (...) you can feel like you are drowning. You just want to scream "shut up" at the top of your voice to make them just listen and not talk.

It was clear Ann was perceived by others as taking the wrong route with regards to her genetic status. Interestingly, Ann's cousin had refused genetic testing yet still proposed Ann should undergo RRS in light of her BRCA2 status, which served to highlight the

complexity surrounding genetic testing for familial cancer. Likewise Susan explained how other people's reactions caused her to feel guilty;

People also always make you feel dead [really] guilty for not having it [surgery] done (...) as if you don't care about your child. My mum said "if you can't do it for yourself at least do it for Emma, you need to be here for her", as if I didn't know.

Susan demonstrated how her decision to refuse RRS was perceived by others to be uncaring and a decision which failed to take into account Susan's duty to her daughter by staying alive for her. Mary also explained how she was made to feel guilty and reminded of her duty to safeguard others, especially children;

(...) but other people were sometimes not so nice. I did get the old guilt trip (...) people with their opinions again about how I was crazy, avoiding something which could save my life. The guilt trip about the kids and the grandwean [grandchild], staying alive for them.

The analysis in this section supports an emerging body of literature on genetic responsibility (Acero, 2012; Douglas, Hamilton & Grubs, 2009; Hallowell, 1999; Hamilton, 2012; Konrad, 2005; Novas & Rose, 2000; Lemke, 2004; Raz & Schicktanz, 2009; Resnik, 2014; Steinberg, 1996; Taylor, 2004; Weiner, 2011) which permeates genetics and provides a means for shaping responses to genetic risk in terms of moral negotiation and how risk is managed (Arribas-Ayllon, Sarangi & Clarke, 2008). Weiner (2011, p. 1760) defined genetic responsibility as "the responsibility to know and manage one's own genome for oneself and the sake of others, focussing particularly on responsibilities to family and kin". In keeping with this, the findings from this study suggested high risk women shoulder a substantial genetic responsibility to their families as a result of gendered ideologies and women's special status as nurturers and gatekeepers of family health. It is not difficult to understand why a woman might wish to act to protect her family nor is it difficult to understand why concerned relatives might wish to encourage women to do whatever is perceived as necessary to prevent cancer. However what this study shows is the health choices of high risk women may be constrained by an ideology of genetic responsibility which surpasses personal choice.

Reading the stories of Susan, Ann, Jacqui, Pauline, Rosie and Mary through the lens of MLT allowed genetic responsibility to be understood as a tool through which medicine maintains control of the population and supports technologies which unite health with wealth (Acero, 2012; Birch & Tyfield, 2013; Novas & Rose, 2000). Although genetic responsibility emphasises particular values and moral actions, it is expressed through demand for genetic testing and risk reducing interventions (Lemke, 2006) because genetic status cannot otherwise be known or attended to. Genetic responsibility thus ensures high demand for genetic medicine and associated biotechnologies which are able to be marketed and consumed (Acero, 2012) and is therefore effective in securing the huge economic gains which can be realised through biotechnologies.

The participants' stories also revealed that genetic responsibility was enacted through the responsibility to communicate knowledge of risk to others. Rosie's twin Sheena was diagnosed with left-sided breast cancer while her mother was also undergoing chemotherapy for ovarian cancer. Sheena had refused genetic testing which Rosie explained had led to her mother being pressurised to undergo testing so others in the family could exercise their right to know her genetic status. Rosie described the reaction from her other sister Julie and Julie's husband when Sheena said no to testing;

They've got three girls themselves and they were both like, "you've got to have this done Sheena, it's not fair, we have a right to know if it's going to happen to us". (...) saying I had the right to know as well because I could be affected too and might need treatment, one way or the other for Tom [husband] and Neil's [son] sake (...). But even then I wasn't sure I would want to know but Julie just couldn't get her head round it (...) me not wanting to know. She wouldn't even discuss it. As far as she was concerned it was the only right thing to do so we could be prepared (...) and mum and me were caught in the middle really. Then Julie took it upon herself to speak to the genetics people and when she told them about mum and Auntie Sue, they said mum could get tested to see if they could find the gene in her. So that's what happened. Julie really made mum get it done. She didn't ask her, just told her she was to go because the rest of us had a right to know if it was in us (...) so my mum did it and of course, it came back positive.

Genetic accountability is increasingly used to support agendas which purport an entitlements-based discourse of rights (Cahill, 2001; Faulkner, 2012; Novas & Rose, 2000) where beliefs about an individual's right to know, right to decide and right to treatment dominate. Rosie's excerpt above highlighted how knowledge of genetic status was perceived as both a right and a necessity by others, even when the affected individuals did not necessarily wish to know their status. Ann also referred to her estranged brother Rob's right to know the family's genetic status which placed a responsibility on her to facilitate this;

Then there was also Rob [Ann's estranged brother] to think about if men can get it. Rob had some problems years back and we've not had contact from him for quite a while but it has made me think maybe I should be trying to find him. I mean he's got a right to know about this gene and for all I know, he could have daughters too which is even more of a worry (...) so I've been trying to track him down but with no joy as yet.

The 'right to know' genetic information is underscored by medical discourse which assumes knowledge of risk factors improves health outcomes (Crabb, 2006; Paul et al., 2014) because people can then do what is necessary to reduce risk (Griffiths et al., 2010; Press et al., 2000) and gain protection from potential future harms (Lock & Nguyen, 2010; Tamir, 2010). Finding out and communicating genetic information is thus not only sensible, but the hallmark of a loving, caring family relationship. This was eloquently captured by Mary who explained how her love for her children influenced her decision to be tested but also the negative impact her test result had on her and her family:

This whole nightmare is not something I would wish on my worst enemy. I really don't see the point in everyone knowing what's ahead for them. I mean, who really wants to know what they are going to be struck down with, what bad things might happen to them. Maybe I shouldn't have let them talk me into it [genetic testing] but you are really caught, torn in two really. You love your kids yeah, so you want to do everything for them, everything possible to protect them but really you can't protect them from this. There is no protection [be]cause you're damned if you do and damned if you don't. But everyone's going on, they've got a right to know, and you love them so you get tested, for them as much as yourself. (...). And now my lassies [daughters] are faced with the same problem because I've got the gene, they have to wait and watch and see if it [cancer] happens to me, and they've got to think about testing. My

oldest doesn't talk about it but then she's got a toddler to keep her occupied and she works too. She's the type to just ignore things and hope they go away. Not like Lisa [youngest daughter]. She is always going on about it, what if she's got it. She's even saying if she gets tested and has it, she's not having children in case she passes it on which makes me feel real bad. I've passed it on to her if she does get it (...) well it feels like it's my fault. If we had never had the tests, we'd be none the wiser (...) I wish I didn't know.

Mary was clearly reluctant to uncover her genetic status yet was "talked into" finding out through pressure from others. Here we see a tension between Mary's genetic responsibility to others and her own autonomous decision making. Ultimately, despite her own misgivings, Mary was persuaded to be tested because others had a right to know her genetic status and because she bore a genetic responsibility to them, a decision she now appears to deeply regret. Mary stated she wished she did not know her genetic status. However, the rights discourse which underscores an individual's genetic responsibility to others ensures risk is communicated to facilitate risk reduction (Lemke, 2006; Paul et al., 2014). Consequently, the right not to know and hence not to engage with risk reducing strategies, does not enter into ideology. Somewhat paradoxically, the right to know genetic information also serves to deny the right *not* to know (Paul et al., 2014). Susan said:

But she didn't tell anyone [she was having a genetic test], not even Elaine and Claire, they're her girls, my cousins. She says now she didn't want to worry anyone and you can see where she's coming from but they were really bealing [angry], they were raging she didn't tell them. I mean, it's a big thing isn't it? It affects them too well it affects us all really. (...) I told her I wasn't happy at the way it was done. We didn't get any warning or anything. I wasn't sure I wanted to know but she just told me "don't shoot the messenger" and made out it was information we had to have, so we could do what was needed to keep us safe from cancer.

Susan's experience illustrated how there was no prior discussion about genetic testing before being informed her aunt carried a BRCA mutation. Instead, her aunt constructed herself as the transmitter of important genetic information which the family had a right to know to protect them from cancer, effectively denying Susan the right 'not to know'. From a Marxist perspective, the rights discourse ensures knowledge of risk is widely communicated and supports an ideology of risk in which individuals are able to

modify their risk of cancer through the consumption of medical and pharmaceutical interventions. Simply put, doing nothing in response to cancer risk does not generate economic yield. Thus it appears ideologies of genetic responsibility and people's right to know take primacy in decision making around genetic testing and risk reducing interventions. Moreover, the stories of Rosie, Ann, Jacqui, Ann, Mary and Pauline show how the ideology of genetic responsibility encompassed doing 'the right thing' in response to risk in order to protect others. The participants were often reminded of their autonomy in decision making, but at the same time, there was a perception some decisions were more acceptable than others. Jacqui explained:

I really did think I would go for it [surgery]. You know it's the right thing to do. (...). Beth [sister] pleaded with me, told me I was crazy, making the wrong decision. She said look how bad she had been when she had cancer and I had the chance to avoid it and I should do everything I could, take what they offered. She said I was playing Russian roulette and it was not fair on any of them, she didn't want to watch me go through what she went through (...) what about my children, all that stuff. Paul [husband] wasn't much better. He would just say "it's your decision, do what's right for you", but at the same time, I always felt he wanted me to do what they [health care professionals] wanted, which was to be a good girl and take the surgery.

The emotional conflict experienced by Jacqui is evident here: she acknowledges RRS as "the right thing to do" because it could potentially protect her and her children from the experience of cancer, yet ultimately she was unable to go through with surgery. Her sister tried to influence her decision whereas her husband emphasised her autonomy with regards to RRS. However despite this, Jacqui's perception was her husband thought she should have RRS because he perceived it to be medically necessary. By describing those who accept surgery as 'good', Jacqui consequently identified herself as 'bad' as she said no to RRS.

The usefulness of Marx's concept of ideology is exemplified in the ways in which genetic responsibility directs high risk women down a particular course of action to deal with the risk of cancer. In Western medicine, 'good' patients are those who accept their illness or condition and acquiesce to the requirements of the medical institution (Ferrie,

2010). Medicine is the legitimate caretaker of establishing sickness and how it should be managed (Bilton et al., 2002; Conrad, 2005), therefore the 'right' health choice is one which conforms to medical discourse and treatment ideologies for the management of risk.

Pauline, Ann and Rosie also at some point referred to genetic testing and RRS as the 'right thing' either in terms of their own perceptions or the perceptions of loved ones.

Rosie explained:

(...) so it seemed like the right thing to do [genetic testing]. (...) when your results come back, family and your friends all seem to think the only option is to have the surgery (...) you'd be mad *not* [said with emphasis] to have it and you should just do the right thing (...) for the sake of your family I've had people say to me I'm *lucky*, [said with emphasis] lucky [raised voice]! Lucky I can do something about it. Well if it is luck it's all bad!

In this excerpt, the dominance of treatment ideologies for cancer risk is evidenced through Rosie being constructed by others as 'lucky' for knowing she is high risk of developing breast/ovarian cancer because she could now undergo RRS in response to risk. The framing of RRS as the only rational option underscores it as the right course of action. Saying no to surgery is therefore the wrong course of action, construed as madness and clearly not in the interests of Rosie or her family. Paradoxically, to act autonomously is to attend to cancer risk by doing 'the right thing', a phrase which effectively functions as a colloquial idiom which indicates a particular acceptable action.

Women are not held personally accountable for their genetic material but are held responsible for the actions taken or avoided to manage genetic risks (Hallowell & Lawton, 2002; Lemke, 2006; Press et al., 2000; Resnik, 2014). Refusing medical intervention was seen as an irrational rather than an autonomous choice (Bishop & Yardley, 2004; Resnik, 2014). Simply put, the autonomous choice becomes the rational choice, but ideology ensures that the rational choice is never free from external influence. The rational choice is that which is ideologically sound and which

acquiesces to the institute of medicine. Hence the responsible/moral subject becomes the economic/rational subject (Lemke, 2006) because irrational actions are non-acceptable behaviours which threaten the State and the prevailing rational order (Lim, 2011). Problematic to this is that such constructions fail to consider underlying structures of exploitation for commercial gain (Thomas-Pollei, 2008). Interpreting the women's stories through the lens of MLT then illuminated the relationship between the ideology of genetic responsibility, autonomy and the rights discourse in relation to HBOC and reasoned this was necessary to ensure growing demand for wealth generating risk reducing interventions.

In summary, MLT analysis suggested a number of enabling ideologies existed which influenced and constrained the participants' decisions in relation to HBOC. The language of cancer genetics was understood as an ideological tool which endowed risk with a material reality and suggested medicine had discovered why women develop breast/ovarian cancer. An ideology of genetic responsibility ensured women were directed to respond to cancer risk in the desired way and ensured the rights of others to attain genetic information to attend to risk were also addressed. This mesh of ideologies allows the commercial exploitation of cancer fear and ensures demand for biotechnologies and risk reducing interventions which maintain and expand the cancer industry. However, despite the dominance of treatment ideologies for dealing with cancer risk, Rosie, Mary, Pauline, Jacqui, Susan and Ann said no to RRS. It was, therefore, necessary to explore the participants' stories for the influence of other dominant discourses and ideologies which shape human experience in Western society.

To this end, the next section turns to an analysis of participants' stories using Marx's concept of commodification. Participants revealed the ways in which their breasts and

bodies had been turned into commodities to be sold to medical technologies that confirm or deny their experiences in relation to being at high risk of developing HBOC.

Breasts, ovaries and commodification

Ideologies of cancer risk and fear are important drivers of health care consumerism and the resulting commodification of women's bodies, since risk makes body parts disposable (Ettore et al., 2006). Additionally, breasts and ovaries hold special status in Western society prompting an analysis of the participants' stories for the effects of dominant discourses of sexuality, femininity and female attractiveness which objectify and commodify women's bodies through the creation of normative standards to which women are expected to conform (Cromptvoets, 2012; Emilee et al., 2010; Peterson, 2007).

The usefulness of Marx's ideas of commodification was exemplified in the ways in which women's bodies were constructed to create an image of an idealised female body which served as a marketable commodity. To this end, images of the idealised female body are used to sell everything from shampoo to chain saws, cars to bottles of beer (Kilbourne, 2012). Rosie was aware that 'sex sells' and the omnipresence of women's bodies in the marketplace:

Everywhere you look it's all 'tits 'n' ass', sex sells, doesn't it? So there's the whole thing with how you look, as a woman (...) which sounds like you are putting your looks before your health. I couldn't explain to people though, they wouldn't understand would they? But how would they feel if they thought they were going to look, you know, no breasts, like that? (...) I couldn't face the thought of it.

Rosie explained the importance of her breasts to how she saw herself as a woman, but also acknowledged women are commodified through the use of particular body parts (in this case breasts and buttocks) to sell goods in consumer culture. The concept of the idealised female body is integral to consumerist ideology in Western society (Peterson, 2007). Consequently, capitalism promotes normative gender ideologies

which define what is considered attractive and appealing in the female gender (Cox, 2011) and subsequently endorse a particular aesthetic in relation to how a woman should look (Adams, 2010). Hence, it was not difficult to understand why Rosie was acutely aware of the importance of her breasts in how she measured up to the ideal woman. Rosie's unquestioning acceptance of the commodified, idealised female image resulted in a tension between protecting her breasts and her health because the thought of breast loss was so worrying. Similarly, Susan revealed the prominence of an idealised female image and how such images impacted on her thinking at the time:

At the start when I was thinking of going for surgery, well it really hits home what is being asked of you, removing your breasts, it's massive, a massive thing to do. I was separated at the time, on my own, but even still. It was like they [breasts] were suddenly everywhere. Wherever you are, they're all over the place (...) women's breasts, boobs selling cars, Wonderbra adverts, all that sort of stuff. It's like a constant reminder of what you are giving up. There's massive pressure on women to look sexy, to be like a certain way, isn't there? It's bad enough when you have them [breasts] so I can't imagine how sh*t it must be for those poor women without them. So, well, why would anyone want to be without them?

In this excerpt, Susan tied being breasted to sexual attractiveness and as a result, the thought of breast loss through RRS was inconceivable. Like Rosie, Susan was aware 'sex sells' (Kilbourne, 2012) and the highly visible images of idealised women's bodies and breasts resulted in her feeling compelled to look a certain way. A mastectomised body is inconsistent with what Susan took to be a socially acceptable female body as verified through imagery in her everyday life.

How women should look is implicit in everyday discourses (Cox, 2011; Gallagher & Pecot-Hebert, 2007) and women are confronted with idealised images of commodified female bodies on a daily basis through advertisements, the media and art (Piot-Ziegler, Sassi, Raffoul & Delaloye, 2010). Ironically, Haines et al. (2010) found idealised images of the female body were also emphasised in breast cancer literature with sexualised images comparable to the imagery used in commercial advertising predominant. Likewise Wilkinson (2001) drew attention to breast cancer awareness

publicity campaigns which used images of conventionally attractive models with mastectomy scars super-imposed onto their torsos, rather than images of 'real' women with breast loss. Such idealised images reinforce the physical differences which occur through breast loss and invite comparisons to sociocultural norms in relation to the female body. Mary explained:

After my test results, I wasn't sure what I was going to do. Surgery was an option and I swithered between yes and no. But then, the idea of surgery was hard, there was some self-pity if I'm honest, a lot of "why me"? I don't want to. So it's really hard. It didn't help that everywhere you look there's these, you know adverts and stuff, with beautiful, perfect women and their perfect breasts. It hurt to see them. Even now I get quite angry when I see them. You see them everywhere and it makes you think about things differently. It's hard to explain. Deep down it's always been like that, but when you think you might not have breasts anymore, it's like a crushing realisation, you suddenly become hyper aware (...) over sensitive about your breasts, and really want to hold onto them [breasts].

Like Susan and Rosie, Mary was acutely aware of idealised images of the female body which were commonplace in everyday life and served as an indication of what was socially expected from a woman's appearance. The prominence of idealised bodies in the media, advertising and popular culture reduces the body to a commodity with an aesthetic exchange value (Peterson, 2007). Viewed through the lens of MLT, commodification opens the female body up to commercial exploitation. Radin and Sunder (2005) argued that the marketplace was a key site for the transmission of cultural and social ideals with those who control the terms of commodification securing their position as a society's ruling class. Consequently, representations of women's bodies are never objective but rather grounded in ideologies and hegemonic ideals which support the interests of the powerful in society (Gallagher & Pecot-Hebert, 2007).

When women's bodies take on commodity status, they are held to socially prescribed and highly gendered standards of attractiveness and sexuality (Gallagher & Pecot-Hebert, 2007). The importance placed particularly on breasts in Western society emphasises the outward appearance of the female body (Haines et al., 2010; Piot-

Ziegler et al., 2010) and constructs the body in objective and visible terms (Cromptvoets, 2012). Body parts such as breasts are then able to be used to sell the ideal. Body commodification thus links women's breasts problematically to societal and cultural expectations of attractiveness. Jacqui explained how the thought of breast loss was particularly difficult and distressing because it would radically change her outward appearance and perceived attractiveness:

Sometimes it was the little things what set me off. You would put it [surgery] to the back of your mind and be going (...) getting about everyday life as normal as possible then something would trigger it. I remember having a total meltdown one night before a do [party] we were going to just because of my dress. It was what some might say quite revealing but I thought, well it made the best of my chest, you know? I looked really good in it. I always got compliments wearing it. But putting it on that night, I couldn't get it back off again quick enough. I couldn't look at it, I hid it away at the back of the wardrobe. It was just thinking, I couldn't deal with how different I would be, looking down and not having them. Never being able to be proud about them again. I know there's more to life, to me, I'm not stupid but at the same time, I just couldn't bear to be without them.

Jacqui valued her breasts and took a certain pride in her appearance as a result. This pride is corroborated by comments from others in terms of compliments about her body because of her cleavage. Grubs, Parker & Hamilton (2014) argued individuals build self-identity in light of characteristics important to them, in this case having 'good breasts'. Hence, good breasts can be understood as assets which allow women to conform to socially defined expectations of the ideal female body. Indeed, idealised breasts are colloquially referred to as 'good assets'. For Jacqui, to lose her breasts was to lose an asset from which she took pride and pleasure at social events. Jacqui acknowledged she was more than her breasts but none the less, she found the thought of breast loss unbearable because it would effectively de-valued her outward appearance. Thus the loss of her breasts/assets constituted the loss of a socially valued sign of femininity (Schulzke, 2011). Jacqui's story continued as she revealed how her feelings about her breasts influenced her decision to say no to RRS:

I just couldn't go through with it. Too drastic. I mean your breasts are part of you, part of being a woman and I am not over the hill yet, you know (...) and there was nothing wrong with them [breasts], they still

look fine. If I'm honest I was scared of losing them. Paul [husband] was always a breast-man, always liked the big ones, so they [breasts] were important to me, to us. Every woman wants to think she's desirable I suppose (...) and my breasts made me feel desirable.

For Jacqui, her breasts were also important in terms of what was considered to be male expectations of attractiveness. Ann also discussed the value of her breasts in both her perceptions of how she looked and also the meanings attributed to her breasts:

Ken has aged really well, he looks better now than he did when we got married [laughs], so I do like to look good for him. He used to say I had great breasts (...) he was first attracted to me because of my figure and he's always been a boob man, how ironic. And even after having children, mine were still quite good, not droopy or saggy, they've aged quite well. My friend said I am more worried about my looks than living but I don't see it like that. She doesn't understand how important they [breasts] are to me, as a person, as a wife.

Ann benchmarked her physical appearance against her perception of what was valued physically in a woman. Like Jacqui, Ann constructed herself as being attractive and hence valuable because of her breasts and it was clear she also perceived her husband to value her because of her breasts. Ann and Jacqui also acknowledged a particular type of breast was privileged and normalised; 'good' breasts which were not 'saggy' (Emilee et al., 2010) which added to their value as an asset. To this end, interpreting the participants' stories through an MLT lens made visible ideologies which constructed women, their bodies and breasts as objects with an associated value in a system of exchange.

Female breasts are important signifiers in Western society and serve as a visible indication of femininity, motherhood and sexuality (Ehlers & Krupar, 2012; Piot-Ziegler et al., 2010) hence are subject to intense public scrutiny and evaluation (Chan, 2010; Spadola, 1998). The value attached to breasts is reflected in the relationship between women's bodies and breasts and socially determined standards of femininity, beauty and attractiveness in Western society (Cobb & Starr, 2012; Thomas, 2006). Simply, breasts are 'exchanged' for an acceptable body image and certain social status. This

means the potential loss of breasts through RRS poses a devastating threat to high risk women.

Commodifying body parts in terms of their value fragments the body and constructs body parts as objects of variable worth which are then able to be accentuated or disregarded (Gallagher & Pecot-Hebert, 2007). Although differences existed in how participants discussed their bodies, all constructed particular body parts as assets.

Rosie explained;

I'm not even that bothered about them [breasts], mine are really small and not really what I would say my best feature, not a lot more than nipples really, but they are still there. Tom always said he was more of a leg man, they were my best feature. It was more about losing my ovaries as to me, that's what makes you a woman. I mean, men have breasts don't they, but they don't have ovaries. So for me, having ovaries was what made me a woman. Without them, I wouldn't feel like I was a woman. I'd be like, well like a non-woman [be]cause I wouldn't be a man and it wouldn't be natural, like the menopause. So yeah, it was more about the ovaries really.

Here several references to body parts and their value as assets are evident. Rosie appeared ambivalent about the value of her breasts because they contrasted with the ideal in so much as they were 'really small' hence not her 'best feature'. Rosie constructed her legs as valuable assets because they were her best feature and source of attractiveness to her husband Tom. Rosie framed her ovaries as assets because they were the essential defining feature of womanhood, therefore to lose one's ovaries was to become a 'non-woman'. The ovaries hence play an important ideological role in defining women because women's bodies are valued for their reproductive potential (Sharp, 2000), symbolise womanhood and as such are associated with femininity and sexuality (Gubar, 2012). Pauline also discussed concerns about the removal of her ovaries:

The thought of the menopause and all the side effects, getting fat, night sweats, growing a moustache, losing your sex drive then add in, you become a moody cow, for a while anyway, so everyone's got to put up with that too. So you look hellish, you feel hellish then to top it all, there's depression and all sorts maybe going on too. I was worried it

would make me look and be old, maybe vanity you might say (...) but no thanks.

Pauline articulated ways in which ovarian loss would damage her physical and emotional health. Oophorectomy and resulting oestrogen deprivation are known to change women's bodies (Bresser, 2009) negatively impacting on physical and emotional well-being (Bonadies et al., 2011; Fry et al., 2001b; Guillem et al., 2006; Hallowell et al., 2012). However Pauline constructed these potential impacts as being in opposition to the idealised female body image in Western society: a slim, hair-free, youthful body (Ashikali & Dittmar, 2012; Jones et al., 2005) and an upbeat disposition (Wilkinson, 2001). This is further evidence of how women and their body parts are commodified and constructed in terms of assets which increase or reduce the social value of a woman. Breasts and ovaries signify femininity, sexuality and womanliness and are thus a form of currency which can be exchanged for social acceptance and desirability (Parry, 2008). By constructing certain body parts as assets of varying value, Jacqui, Ann, Pauline and Rosie could be argued to be complicit in their own commodification. From a Marxist perspective, this occurs because the gendered structure of capitalism disproportionately targets and commodifies women (Adams, 2010; Cox, 2011) in order to promote body insecurities (Peterson, 2007), stimulate consumerism (Cromptvoets, 2012) and create profit (Allan, 1998). Moreover, so-called 'common sense' beliefs about how women should look conceal ideologies which draw on normative notions of womanhood, femininity and sexuality and thus appear natural and given (Bennett & Royle, 1999). Susan explained:

The main issue I think is how you would look after [mastectomy]. It just seemed so drastic to have so much surgery when there's nothing wrong with you. It changes everything. Every woman wants to think she looks good. No-one wants to think they are not attractive do they? And like it or not, as a woman your breasts are a big part of that, so it's really a terrible position to be in.

Susan's story reproduced two key ideological influences. First, breasts are inherently and essentially tied to female attractiveness. Second, women innately strive to be attractive to others. It is the very 'naturalness' of such ideologies which encourage

women to internalise socially determined acceptable standards of beauty and sexual attractiveness in Western society (Coco, 1994; Cox, 2011; Riessman, 1983; Serdar, 2006; Thomas-Pollei, 2008) and to value themselves accordingly.

The participants, in this study, assessed their value as a woman largely in terms of the presence and condition of their breasts and ovaries. Marx's ideas of commodification were useful in understanding breasts and ovaries as assets which gave value to a woman's body or through ways in which women were constructed as being less valuable without breasts and ovaries (Gallagher & Pecot-Hebert, 2007). It is not surprising, therefore, potential breast/ovarian loss caused Rosie, Ann, Pauline, Jacqui, Susan and Mary to question how valuable their post-surgery bodies would be and how the loss of their 'assets' might impact on their lives. All voiced concerns breast and/or ovarian loss would negatively impact on how others saw them and damage current or future sexual relations. Rosie discussed her fears related to the removal of her breasts:

Tom and me, well without going into the gory details, we were still very sexual in our relationship (...) still enjoying that side of things at the time. With Neil being a teenager, we had been having a bit more freedom that way [sexually] again with having the house to ourselves a lot. If I had (...) [points to breasts and makes cutting off gesture], every day I would be thinking, "I'm not a whole woman, it's not me". Tom said it wouldn't bother him but it would bother *me* [said with emphasis]. I wouldn't be able to let him see me, look at me again, I don't think.

Rosie believed breast loss would impact negatively on her body image to the extent she would have to shield her post-surgery body from her husband, despite his reassurances to the contrary. Mary also described her belief breast loss would diminish how attractive she was to her partner:

Robert [husband] of course said it wouldn't matter to him what I looked like, but a man is going to say that isn't he? I mean, he wouldn't be much of a man if he said, "don't you dare have them off, I won't fancy you after". No-one's going to actually say it. But it's how I would feel, I wouldn't feel fanciable. I wouldn't feel like a woman.

Like Rosie, Mary questioned the reassurance offered by her husband. Self-image was so closely bound to perceptions of what makes a woman attractive, they thought they would be less sexually attractive following breast loss. Rubin and Tanenbaum (2011) found that breast loss in particular was equated with a loss of sexual identity and attractiveness. Studies also show women often wrongly assumed their partners would be repulsed by their mastectomised bodies (Sheppard & Ely, 2008; Sulik, 2012) and continued to harbour negative thoughts even when partners offered reassurance this was not the case (Bertero, 2002). Gallagher and Pecot-Hebert (2007) contended culturally determined standards of attractiveness encouraged women to define themselves in relation to their relationships with partners and male expectations of appearance and attractiveness, therefore a perceived loss of attractiveness was likely to be translated as a failure to meet male expectations. Susan, a single parent at the time of interviews, explained such perceptions thus:

At first I was going to have it done, the mastectomies and the ovaries because Emma is my priority and I'm not really wanting any more children, don't have a man anyway [laughs], and no-one would want me with no chest anyway. I mean it's not a priority for me by any means, but you never know, Mr Right might be waiting round that corner and if he is, well, it wouldn't be a very good start would it? Nothing down there [points to chest]. I wouldn't be much of a catch with no women's bits, would I? [laughs]

Although Susan laughed as she discussed not being a good 'catch', her story demonstrated how the social value of women may be reduced as a result of breast/ovarian loss. Susan's perception of her post-surgery body was problematically linked to her perceptions of male expectations of attractiveness hence she constructed her changed body as unfit for consumption in the marketplace for attracting a partner.

The significance of the male gaze was captured in the stories of Rosie, Ann, Pauline, Jacqui, Susan and Mary. Women facing breast loss fear their bodies will shock partners and experience doubt about submitting themselves to the male gaze (Szumacher, 2006), describing their breastless bodies as hideous, undesirable and

monster-like (Piot-Ziegler et al., 2010). Drawing from Marx's concept of commodification, not only are breast/ovaries commodified as assets of varying worth, but consequently women without these assets are constructed as 'damaged goods'. Jacqui explained her thoughts on breast loss in the context of her relationship with her husband:

I know he [husband] loves me and it feels stupid even saying it, of course he would, but I needed reassurance we would be okay and he would love me boobs or no boobs, because you know he loves you but it doesn't stop the voice in your head going on and on. You'd be different somehow, incomplete. Not the woman he married.

Here, it was apparent Jacqui's breasts and what they symbolised formed an important part of her self-image (Hallowell et al., 2012). To lose her breasts meant she would become a different woman, an incomplete woman. Numerous studies have identified women facing breast loss worry about being perceived as damaged goods (Esplen, Stuckless, Berk, Butler & Gallinger, 2009; Grubs et al., 2014; Hamilton, 2012; Hoggan, 2014; Karp et al., 1999; MacDonald, Sarna, Weitzel & Ferrell, 2010; Robinson & Lounberry, 2010; Sadeh-Tassa, Drory, Ginzburg, & Stadler, 2000; Spiegel & Classen, 2000). Women facing breast loss construct post-surgery bodies as unattractive, abnormal or damaged (Cromptvoets, 2006; 2012); ugly (Bertero, 2002), handicapped or incomplete (Piot-Ziegler et al., 2010) and disfigured or deformed (Freysteinson et al., 2012).

The concept of 'damaged goods' is made possible through a Marxist interpretation and links between women's concerns about becoming breast-free and the value placed on retaining breasts are evidenced. When breasts are commoditised as body 'assets', it stands that bodies which lose assets are damaged. Pauline touchingly outlined the impact being damaged could have on her life:

Our 'thing' is to have a bath together and take a bottle of wine in (...) it's how we relax or what we do if we get a night away together and it would be out the window. A really special thing for us and it would be totally ruined. Sarah [sister] has told me she feels the same, she doesn't feel attractive any more, even though her husband is trying to be supportive

about it. (...) John said I should do what I want and he wouldn't mind but I know he would. What man wouldn't? And even if he didn't mind, I would mind and I would lose all confidence in myself. I would never be undressed in front of him again.

Pauline subliminally framed herself as damaged goods when she explained she would no longer feel attractive to her husband should she lose her breasts. She was therefore forced to call into question aspects of her relationship with which she was previously confident of, as a consequence of the anticipated bodily changes incurred through RRS. A perception of the body being damaged goods was also evident in the ways participants referred to the bodies of others. Although not always openly acknowledged, mastectomy in particular was perceived as damaging the body. Rosie explained:

I've seen Sheena's [sister] [points to breast area] and I don't like saying this, but it's not pretty. I couldn't cope with looking [shrugs shoulders], you know, if I didn't need to. It would be different if I actually had cancer. (...) I don't like saying this because it's saying something bad about other women who have had to have it [mastectomy] done, which I don't mean, but I would think I looked [makes 'squeamish' face], you know?

Rosie had trouble articulating her thoughts about how she might look following RRS although it was clear from her silences and body language the thought of breast loss was almost too difficult to imagine. In this next excerpt, Jacqui shared an experience from her childhood which poignantly revealed how a woman with breast cancer was rather cruelly reduced to a description of her mastectomised body:

I remember being at high school and there was this teacher, she taught home ec [economics], everyone used to call her rubber tit and wooden tit. She had breast cancer. God I cringe now when I think about it (...) what terrible, nasty things. The boys used to throw toilet roll at her, you know, sniggering and saying behind her back to stuff her bra. We all laughed but, well I didn't really know what they meant, it was older kids. Then someone told me (...) but even then, I was only about 13, I suppose I just shrugged it off. Then when Beth [sister] had to have her breast off, for some reason I remembered back, Miss Wilson, and I could weep for her, for what happened. It must have been hideous, having cancer, losing your breast then having to cope with that sh*t. I just couldn't think of myself like that (...) looking *that* [said with emphasis] way. I don't even like to think about being like that.

Jacqui's fear of breast loss arose in part from a negative experience of a mastectomised body from her childhood, and like Rosie, she was unable to imagine

her own body in this way. Although Rosie, Jacqui, Ann, Pauline, Susan and Mary recounted different meanings and understanding of their experiences of facing breast loss, all saw their post-surgical body's as 'damaged goods' in some way.

The participants' stories revealed high risk women's responses to breast and ovarian loss are multiple, conflicting and complex. Marx's ideas on commodification provided a useful framework for interpreting the participants' stories within the context of everyday discourses in Western society which shape and influence human experience. Rosie, Jacqui, Ann, Pauline, Susan and Mary's conscious reflections on the fear of breast/ovarian loss support gender and sexual ideologies but contrast with medical ideologies which position breast/ovarian loss as a necessary and somewhat pragmatic step in dealing with cancer risk. However, medical ideology does also attend to breast loss, and the premise of the perfect female form by offering breast reconstruction as a necessary procedure to repair damaged bodies following mastectomy. The next section explores this notion in detail and situates breast reconstruction within wider frameworks of understanding which expose ways in which reconstruction is ideologically and economically driven and how the institution of medicine is complicit in the commodification of women's breasts.

Commodification and breast reconstruction

In the previous section, an interpretation of the participants' stories through the lens of MLT suggested breasts and ovaries are commodified as bodily assets hence bodies without these assets are able to be constructed in ideology as damaged. Accordingly, breast reconstruction following RRM, herein referred to as 'reconstruction', can be understood as a means of repairing damaged bodies. Furthermore, this interpretation contends that reconstruction is a manifestation of commodification since it is the means through which bodies at risk of cancer can be rendered safe and repaired through the procurement of reconstructed breasts in exchange for high risk breasts. Simply,

commodification of the female body/breasts is expressed through the consumption of reconstructive surgery.

Reconstruction is inextricably embedded in medical ideology (Gallagher & Pecot-Hebert, 2007; Sulik, 2012) and participants were encouraged to consider reconstruction as part of the package of cure for cancer risk. Mary described being “sent” for counselling and her perception surgery was the assumed outcome following the testing and counselling process:

Early on I considered it [surgery] and you get sent to see a counsellor and a breast care nurse, so you talk through lots of things, about coping, losing your breasts and ovaries, the menopause and things. I think when they send you for counselling, at this point it's assumed you are going through with it (...) the surgery talk is ramped up, the choices of implants or expanders, all about that. Not having surgery didn't appear to be even on the radar.

Although Mary was still undecided about RRS, the potential for reconstruction was introduced early on in her HBOC journey. Mary recalled seeing various health care professionals and being offered information about different types of reconstruction surgery on the assumption she would undergo RRS hence reconstruction to replace breast loss would be necessary.

The essential nature of reconstruction after breast loss is apparent in public, consumerist and health-related literature (Cromptvoets, 2006, 2012; Haines et al., 2010; O'Neill, 2013; Sulik, 2012; Wilkinson, 2001). Reconstruction is framed as something all women want (Cromptvoets, 2006) and calls are made by plastic surgeons for the ‘under-utilisation’ of reconstruction to be addressed through policy and fiscal measures (Alderman, Storey, Nair & Chung, 2009). Official guidelines such as NICE (2013) state reconstruction must be made available to all women facing mastectomy. Reconstruction is framed as an inherently positive offering and a “beacon of hope” (Cromptvoets, 2006, p. 76) in a woman's journey of recovery following breast loss. The

only reasons for not undergoing reconstruction are purported to be financial or the presence of co-morbidities.

All participants referred to reconstruction in some way and it was evident that reconstruction was presented to participants as another key step in the management of HBOC. Susan revealed that reconstruction was offered to her during preliminary medical consultations:

They said my risk of breast cancer was higher but because mum had ovarian cancer, to think about that too. You need to see a plastic surgeon, and a psychologist. And if you have surgery you need implants, or I think they said there was other types [of reconstruction], using your own (...) fat from your stomach type of thing.

In her own words, Susan framed the option of reconstruction as a necessity: she 'needed' to see a plastic surgeon and would 'need' an implant or some other form of reconstruction if she accepted surgery. Like Mary, Susan acknowledged reconstruction as something women facing breast loss must be concerned with to repair the body following surgery.

From a Marxist perspective, the commodification of women's breasts and bodies is enabled through reconstruction ideology which reifies its importance in facilitating recovery from breast loss. In fact, it is generally framed as the only means through which women can overcome the assumed negative self-image following breast loss (Cromptvoets, 2006). To this end, this discourse implicitly and explicitly constructs reconstruction as potentially disparaging of breastless bodies. Breast loss is presented as a disabling abnormality (Cromptvoets, 2012) which creates a gender crisis (Báez-Hernández, 2009) and causes a loss of femininity, sexuality and (Emilee et al., 2010). Moreover, breast loss is branded as so personally and publically alarming, it must be camouflaged (Báez-Hernández, 2009; Rubin & Tanenbaum, 2011) or hidden from sight (O'Neill, 2013; Wilkinson, 2001) so that women appear unaffected and unchanged by surgery (Schulzke, 2011). Cromptvoets (2012) further argued that the construction of

breast loss as abnormal and disabling and something which must be concealed is heavily marketed by various stakeholders in restoration technologies and taken up in consumer and public discourse. Thus, the need to exhibit a 'normal' appearance which disguises breast loss is continually presented to women, albeit very subtly at times:

But the family all seemed to think I would jump at the surgery. Ken was really good but I could tell he thought I should have it [surgery] even though he said he would support whatever decision I made, but you can just tell. He would make comments about people who had the surgery [mastectomy] and say how good they looked. He would never have said anything before. I remember Kylie Minogue had been treated for breast cancer and Ken was talking about how good she looked, and "you would never know" (...) if she was ever on television. (Ann)

Although Kylie Minogue did not undergo mastectomy but lumpectomy, Ann's husband attempts to offer comfort to Ann by suggesting women can be treated for breast cancer and still maintain a normal, attractive outward appearance. Reconstruction is presented and reinforced as a means through which women facing breast loss can repair their damaged bodies and look 'normal', bestowing reconstruction with an aura of necessity.

Evidence suggests RRM with reconstruction is becoming increasingly prominent with almost 70% of women having RRM also having reconstruction (Semple et al., 2013). Mary also discussed the considerable effort women facing breast loss take to attend to their post-surgical bodies:

I went online to ask other women about it [experiences of surgery]. There were umpteen stories about tissue expanders, implants, nipple reconstructions and tattoos. Unreal. On one website there was even pictures women had put up to show their new boobs. (...) everyone seemed to be getting it done. I was the only one who wasn't too keen I think. It was all a bit weird if I'm honest (...) some of them, it was like they were showing off a bit, you know, "check me out, how great do I look". Well not to me you don't. (...) sure it was probably their way of coping but, no, it wasn't for me.

Mary discussed the commonality of reconstruction and positioned herself in the minority amongst a majority of women for whom reconstruction had been accepted and essentially embraced. The increase in the number of women undergoing

reconstruction following prophylactic mastectomy may in part reflect improvements in reconstructive surgical techniques which make surgery more appealing (Peled et al., 2013) such as nipple and areolar-sparing techniques which give an improved cosmetic result (Spear et al., 2011). However, an alternative position is offered by Cobb and Starr (2012) who drew parallels with the cosmetic surgery industry in so much as both cosmetic and reconstructive breast surgery are socially mandated but medically unnecessary procedures, making them both aesthetic practices which generate significant profit.

In the same vein, Gallagher & Pecot-Hebert (2007) argued that a makeover culture which normalised and glamorised cosmetic surgery in the name of self-improvement existed which now also served as a mode of reference for women facing breast loss. In contemporary culture, reconstructive surgery for breast loss is now strongly affiliated with cosmetic surgery, itself a routine and acceptable means of achieving self-improvement and self-image (Löwy, 2010). Susan recounted:

But everyone tells you it's a no-brainer. Take the surgery, get the implants and you'll probably look better than you did before. It's as if it's no big deal, like you are some sort of celebrity, getting your boobs done (...) like out of choice or something. Thanks very much! There's nothing wrong with mine [breasts]!

In this excerpt, Susan explains how RRS and reconstruction was constructed as a straightforward procedure from which she could potentially gain body improvement. Although Susan was satisfied with her natural breasts, she was encouraged to think her breasts could be better with implants, a perception which appeared to reflect the increasing prominence of breast augmentation in popular culture. Rosie similarly explained how her sister suggested she might consider RRS with reconstruction as an opportunity to enlarge her naturally small breasts:

(...) [reconstruction is] a good thing for some women, it would be a comfort, to know, you know that you wouldn't be left with nothing (...) you'd still have something there, a proper shape. But it didn't really bother me too much with mine [breasts] only being little, double As, it's never been a big deal for me, how I looked up top. But then, you don't

want to have nothing at all. Mind you, Sheena [sister] did say I could go bigger, so it could be a good thing, getting implants. But it wasn't about that for me. I was happy the way I was.

Cobb and Starr (2012) also proposed the discourse surrounding reconstruction is comparable to that of cosmetic surgery. They built on Ehrenreich's (2001) seminal work 'Welcome to Cancerland' which contended contemporary culture demanded women facing breast loss exhibit a particular type of experience and participate in the experience as a form of makeover and self-improvement from which they can emerge prettier, sexier and more feminine. The makeover discourse exploits body insecurities and promotes improvement through the consumption of lotions, creams, cosmetics, cosmetic procedures and ultimately through the consumption of reconstruction following breast loss (Cromptvoets, 2012).

The integration of the makeover discourse exposes HBOC as a market driven industry of survivorship (Sulik, 2012) in which reconstruction can be consumed by women facing breast loss so they can regain their value in Western society. This was useful in interpreting the ways in which participants' bodies and breasts were frequently framed in medical encounters as potentially enhanced following reconstruction. Mary said:

The surgeon I saw was very upbeat about it to be honest. I think he thought he was being positive but it bugged me a bit. I was thinking "you're a bit cheery about this, how would you be like if someone wanted to whack your nuts off"? He was like, "you'll be back to normal in six months" like I will I ever [said with emphasis] be normal again. He showed me before and after pictures and made comments, some women look better after. Well I didn't see anything that looked better after.

Mary explained here how her surgeon suggested some women's natural breasts were in need of medical repair by framing reconstructed breasts as potentially looking 'better'. Also, by suggesting reconstruction offers 'normality' in six months, Mary's recovery is centred primarily on her restoring her outward appearance, a claim vehemently rejected by Mary who felt she would never again achieve 'normality'.

Similarly Jacqui outlined a discussion with her GP following her genetic test during which the GP had suggested reconstruction could improve her natural breasts;

He [GP] was really good, understanding (...) he signed me off [work] straight away (...). He was very sympathetic and you didn't feel, like you were being, over-reacting or anything. He was asking if I knew my options but it was too early. Then he goes "oh well, it's not like years ago. They can do so much now and you never know, you might end up with a better pair than before", or words to that effect. It was a bit off putting if I'm honest. I didn't know quite how to take it. I just laughed and said "yeah maybe".

Mary and Jacqui's excerpts indicated that there had been times when health care professionals were complicit in the commodification of their bodies and breasts by presenting reconstruction as a routine intervention which could even be considered a 'bonus' in terms of improving their breasts. Like Susan and Rosie, Mary and Jacqui were encouraged to think of breast removal with reconstruction as a package not only to render their risky bodies safe again, but to consider the process as a package of improvement which could upgrade their bodies. The makeover discourse suggests women at risk of cancer are in a win-win situation: remove cancer risk whilst simultaneously restoring the body to its former glory or even achieving a better body than before. There is, as Löwy (2010, p. 215) found, a promise of "new breasts for the old" which supports the overly optimistic claims attached to reconstruction post-breast loss.

Additionally, it is notable such 'improvements' to the body are universally considered in terms of a socially constructed ideal breast which fits a particular aesthetic. The notion of the 'perfect breast' is highly prevalent in Western society and reinforced by consumer and medical literature which suggests a particular type of breast is ideal hence desired by women (Mallucci & Branford, 2014; 2012). Decades ago, Morgan (1991) argued elective cosmetic surgery was becoming normalised to the extent women not having surgery would come to be viewed as stigmatised and deviant. More contemporary literature reaffirms this and suggests not only is cosmetic surgery

normalised, but also glamorised (Gallagher & Pecot-Hebert, 2007) and routinised as a staple feature of modern life (Adams, 2010). Adams (2010) further contended cosmetic surgery could be understood as a form of commercial medicine which aggressively markets itself to consumers through a mandate of surgical self-improvement. Accordingly, if surgery to correct and improve aged, pendulous, small, unequal, sagging, stretched or any other breast imperfection is routine, then surgery when breasts are removed or missing is likely to be deemed obligatory.

Medical and public literature on breast loss provides little discussion of women deciding not to have reconstruction. A culture of survivorship and optimistic outlook emphasises restoration of the body to 'normality' through reconstruction and denies women the chance to mourn their changed bodies and express anger and fear (Sulik, 2012). No attention is paid to the potential normality of the mastectomised body (Crompvoets, 2012) and the option of *not* concealing breast loss is unavailable to women (Rubin & Tanenbaum, 2011; Wilkinson, 2001). Instead, women facing breast loss are continually presented with options all of which require a renegotiation of the body in relation to the outward appearance (Báez-Hernández, 2009). The prospect women might not want or feel the need for reconstruction rarely, if ever, enters the debate. The market potential of breast cancer is increased through a survivorship culture and reconstruction ideology. From a Marxist stance, this is necessary to ensure a high demand for and consumption of reconstruction and wealth generating medical technologies.

When women undergo reconstruction, ideology conceals the profit making potential available to various stakeholders as part of the way the body is commodified. Thus as O'Neill (2013) contends, reconstruction is promoted as essential in recovery from breast loss but is economically tied to various health care providers. Additionally, ideology conceals the human costs of surgery which include pain, numbness, scarring

and unacceptable physical changes (Rolnick et al, 2007) and failed reconstructions (Koskenvuo et al., 2013) which may require women to undergo numerous surgical procedures. In contrast to the new, improved breasts promised through makeover discourse, reconstructed breasts are found by many to be unpleasant (Gopie et al., 2013) and women report being unprepared for the lack of sensation in their reconstructed breasts (Hallowell et al., 2012).

To conclude this section, an interpretation through the lens of MLT suggested reconstruction was sold as part of the package of cure for cancer risk. Reconstruction effectively serves corporate interests which link ideologies of women's bodies with recovery from breast loss (Cromptvoets, 2012). Reconstruction promises restoration of normality, femininity and sexuality (Cobb & Starr, 2012) hence breasts are further commodified (Sulik, 2012) for the corporate manipulation of what is a life threatening and feared disease (Selleck, 2010). The analysis problematised the framing of reconstruction as essential and routine, and revealed the participants rejected the promise of reconstruction and instead perceived it as a risk to the body. The participants' stories accordingly exposed what is hidden in ideology: RRS potentially damages bodies and reconstruction is limited in what it can offer high risk women in terms of repairing their damaged bodies. This was an important theme which emerged from the study and is discussed in further detail in Chapter 6.

Joining to the role of power in maintaining ideologies

Marxist power is based on economics. However, an understanding of how ideological practices are sustained and exert power to maintain the dominance of certain discourses in relation to cancer and cancer-risk management is best understood by a Foucauldian interpretation of how power is spread through discourse and social relations.

Foucault was critical of the concept of ideology as false consciousness, something unknown or fake which obscured 'true' knowledge. Foucault disagreed with aspects of Marx's ideology mainly in relation to the suggestion man has an innate consciousness which power acts upon. Foucault focussed more on the effects of power on the body and argued there is no such thing as false or true consciousness: we are all the products of culture and history. For Foucault, truths were socially, historically and culturally bound positions which were fluid and ever changing depending on the dominant societal discourses of the time. The next section provides an analysis of the participants' stories from a Foucauldian perspective and reveals further the conflicts and contradictions which bind HBOC management and which influenced the participants' decisions to say no to RRS.

An interpretation through the lens of Foucauldian Literary Theory

Foucault's primary concern related to how individuals came to be constructed as subjects and conform to covert organising practices which constrain and control in modern societies. Foucault argued subjectification was facilitated by modes of power including biopower and disciplinary power which regulated and disciplined individuals in society (Taylor, 2011). Biopower governs populations whilst disciplinary power targets the individual body through various non-coercive techniques and mandates the ways in which individuals exist and act (Hoffman, 2011). Power, from Foucault's perspective is intertwined with authoritative truth because power operates through what people say as much as what they do (Lynch, 2011). Hence discourses create and maintain the rules and norms which define realities for women with BRAC gene mutations and give rise to power relations through the creation of knowledge and truths about why and how they should respond to their mutation-positive status.

The stories of Susan, Ann, Mary, Rosie, Pauline and Jacqui are fraught with their responses to feeling powerless. However, a Foucauldian lens provided an

interpretation of participants' experiences in regards to concepts of power relations, discourse and how knowledge is constructed as power in the medical discourse. A Foucauldian analysis to the participants' stories disrupted taken for granted assumptions about how RRS is understood and exposed discursive elements and power/knowledge relations which shaped their experiences. This approach illuminated the struggles the participants in this study faced as they followed a path at odds with the dominant discourses in which their experiences took place, but also highlighted the possibility for resistance to the dominant medical pathway for HBOC.

Knowledge, truth and the medical discourse

Foucault's concept of discourse posits individuals in society are regulated and controlled through discursive practices which serve as collective organising tools within particular discourses (Bertens, 2008). Discourse is the means by which knowledge is represented and validated as 'truth' hence discourse is intertwined with power since individuals are socialised within discourses (Seymour-Smith, Wetherell & Phoenix, 2002) and therefore their experiences of owning a BRAC1/2 mutation acquire meaning through various discourses.

The findings from this study revealed the effects of irrefutable truths about HBOC which disempowered those who did not conform to the accepted treatment norms and constructed them as aberrant. The participants' stories of medical consultation revealed that medical advice was significant in determining 'the truth' about familial cancer. Mary, Ann and Pauline described prior experiences of family members with cancer and concerns cancer may have been 'passed on', only to have these concerns dismissed by relatives, friends or physicians. However, once genetics was popularised and genetic testing revealed the presence of a BRAC1/2 mutation, their concerns were accepted without question. Mary explained:

So what I had believed about it being a family disease, it was backed up by what the doctors were saying. It made it all official (...) and real. I had been saying it for years and everyone said I was daft, being over dramatic. So part of me felt, well not pleased, that's not the right word (...) but a bit, I'd been proved right. Didn't make it any less scary though (...) more scary now it was official and not just me saying it.

Mary's words evidenced not only how knowledge of her family's disease pattern was dismissed as foolish and melodramatic, but also the power of medical knowledge to determine truth and therefore risk of cancer and necessary actions to combat the genetic risk factor. Ann's story also provided evidence of how medicine determines the truth about cancer;

For as long as I can remember, I've been expecting it to happen to me, so when she [sister] was tested and it came back positive, it really just confirmed what I had always known. (...) Before the test, Ken said it would be good to have it done, then we would know for sure one way or the other, we'd find out the truth. I said I already knew but he said, ... "well you don't really, you just think you do, we need to find out the truth"(...) maybe that's why I was shocked, him saying it made me really think maybe it would be negative and I'd be off the hook. (...). Even though I had deep down knew it would be positive, it was still a shock, the finality of it.

Although Ann felt certain she would be mutation-positive, others dismissed her knowledge as insufficient and it fell to medicine to authenticate this as the truth about her family's cancer status. Ann described her shock once this 'truth' was discovered through genetic testing, her use of the word 'finality' suggested an inevitability which was now unavoidable.

Pauline also discussed how the concerns of women in the family were initially dismissed prior to genetic testing. Pauline's maternal grandmother was first diagnosed with breast cancer in the 1970s and subsequently died from the disease in the early 1980s. Her mother was diagnosed with breast cancer in 2002 but died shortly after from a stroke. Her story showed how her mother's request for RRS was denied despite her mother's belief her cancer was familial:

My mum's mum, she was the first we knew of although after my mum died, it came out there had been others, as far back as the war they said. When mum got hers [breast cancer], she said to the docs, "just

take them both off, just get rid of it". I think she knew then it might be something in our family (...) it really brought it all into focus in a way. They only took the one breast away and then of course she took the stroke and died, so we'll never know if the cancer would have come back. Mum really believed we were cursed by it [cancer], she used to say it was a curse, but back then it wasn't treated the same. They said taking away her good breast was overkill. I thought she should have it off too, you know, just wanting her to be okay (...) but they didn't want to [remove the unaffected breast]. Then Sarah [sister] got it [breast cancer] too and it was a whole different ball game (...) right from the start they were asking about mum and gran and then bringing in me too and the rest of the family. By then, they knew it was passed on through families.

Pauline's story shows how removal of the unaffected contralateral breast was described as 'overkill', highlighting how her mother's knowledge was considered less important than medical knowledge at the time. In medical discourse, concerns about hereditary cancer and requests for RRS were largely not taken seriously prior to the widespread availability of genetic testing (Hamilton, 2012; Happe, 2006). Genetic mutations, as pathological entities, existed but were not branded as risks for disease until technology was developed which allowed mutations to be named, classified and responded to (Lerner, 2000). Lay knowledge was thus dismissed until made visible and accessible through genetics then claimed by medicine as its own.

Matloff, Bonadies, Moyer and Brierley (2014) found cancer genetics specialists' views on genetic testing and RRS changed between 1998, when the speciality was in its infancy, and 2012 as more had become known. Matloff et al. (2014) found as genetic testing became routine, specialists were more accepting of testing and RRS and more likely to accept these measures for themselves. Removal of healthy breasts pre-disease, once considered an "unthinkable step" (Thompson, 1994, p. 38) is now considered the principle primary intervention for reducing breast/ovarian cancer risk (Guillem et al., 2006; Ingham et al., 2013), despite much remaining unknown about the genetics of hereditary cancer (NICE, 2013) and how best to manage people with BRCA1/2 mutations (Kurian et al., 2010). Similarly, contralateral prophylactic mastectomies in women affected with breast cancer, previously denied to women such

as Pauline's mother are now common despite a lack of evidence regarding its efficacy (Newman, 2014). From a Foucauldian perspective, the key point is no permanent or timeless criteria for determining the truth exists. What is problematised is the discourse surrounding medical knowledge which constructs some information as facts which represent 'the truth' about breast/ovarian cancer while other information is relegated to the background. Thus, medical discourse reflects a hierarchy of credibility around HBOC which privileges some types of knowledge over others and supports power relations which endorse RRS.

Not surprisingly then, medical/genetic knowledge validated the women's and their families' concerns about familial cancer and was regarded as the official explanation or 'the truth' about why people develop cancer. Susan's story revealed changing perceptions of the cause of cancer in her family from non-genetic to genetic reasons once testing had taken place;

And I knew by then cancer had taken my granny so you do worry about someone dying from it. The doctors did ask my mum about her mum but nothing was done about it so we just thought we were unlucky getting cancer twice in the family. (...) Plus they both smoked so we just assumed it was maybe the smoking brought the cancer on. Then after my aunt got tested, that showed us (...) the cancer must have been caused by bad genes, probably not through smoking.

Susan came to attribute her mother's and grandmother's cancers entirely to genetic causes, discounting other potential causes as unlikely now the genetic information was known. Again, while this may be understandable given a deleterious mutation was identified in her family, it suggests genetic knowledge was accepted over other knowledge as 'the truth' about why people get cancer despite the greatest majority of breast/ovarian cancer occurring sporadically through non-heritable causes (NICE, 2013). There was some acknowledgement of non-heritable causes of cancer, for example, Pauline alluded to possible environmental causes when she said;

I read on a web site about one woman like me, BRCA2 positive and not having the surgery. She talks about pollution and the environment and how it can cause cancer. (...) now I know [genetic status] I am watching

my diet and trying to be more healthy. Doing things like, trying to avoid chemicals and stuff, things linked to cancer. It's my way of trying to get my risk down and do something positive myself. I think doing something about it yourself makes you feel better.

Similarly Susan and Mary acknowledged there was a link between smoking and cancer but generally, the participants and their families appeared to adopt the genetics discourse as the most likely explanation for cancer. This showed how BRCA1/2 mutations are now normalised in public discourse to the extent they are increasingly considered a concomitant factor in non-inherited causes of breast cancer, reflecting what Ilkilic (2009, p. 140) referred to as a “cultural adoption of meaning”. Ann likewise highlighted the primacy of genetic information as providing ‘the truth’ about cancer and its deadly consequences:

(...) there had to be something that was killing us off. We don't just get cancer, we get terminal cancer so I guess it [gene fault] sort of explained it really. All this cancer was down to our own bodies killing us, (...) an awful thought really.

Foucault would argue that the uncritical acceptance of medical authority and an almost dogmatic belief in inherited genetic causes for cancer is symptomatic of the medical/genetics discourse which gives consent to particular ways of acting in response to cancer risk. Mary said:

When she [Mary's mother] died (...) you didn't really know much about it [breast cancer] back then. We didn't have computers like you do now so you only had what they [health professionals] told you. It was when her sister, my Aunt Yvonne got breast cancer too, well it seemed more than a coincidence. Two sisters both getting it [breast cancer], well it was like lightening striking twice in the same place (...) then when Angela [cousin] got diagnosed too, the doctors seemed to get interested. (...). Of course hers [Angela's genetic test] came back positive for the gene and (...) gave us concrete proof cancer was in our genes, running through our family.

Here, Mary's story reveals two key effects of discourse: the construction of genetic knowledge as ‘the truth’ or as Mary believed, ‘concrete proof’ of why cancer develops, and also the reliance on experts to legitimise concerns about health. Thus, genetic knowledge as the truth is privileged and creates reliance on doctors as experts who regulate the body.

The issue of specialism

Specifically, the medical discourse dictates what is considered the truth or facts about health and disease and who is allowed to speak legitimately about health matters (Stoddart, 2007). From a Foucauldian stance, genetic information and how it is discussed may be understood and delivered as a discursive practice which defines the specialist nature of genetics. Pauline explained:

You need to have quite a few sessions before they even test you. They tell you how they calculate your risk and things (...) it's really specialised information they give you, very complicated. (...) And some of the words they use (...) they give you booklets and web sites but it's quite hard. Without being a medical person, it's really difficult to understand. It was even harder to tell it to John [partner]. He kept asking me questions I couldn't answer. Then he would get all angry, shout at me I needed to ask more if I didn't understand. They didn't let him in [during counselling] because (...) it's privacy and to do with making sure I make my own decision and (...) be totally honest. John got a bit stressed, made me feel a right idiot at times, not knowing. I think that's why I was a bit scared with this [taking part in the interview], worried I wouldn't know the right answers.

Genetics counsellors were frequently referred to as 'the specialists' and there was a perception genetic information could not be challenged because of its 'specialised' nature. Susan said;

At the [genetic] counselling, it's not like seeing a normal doctor, it wasn't like anything I'd ever experienced. You wait ages for an appointment which I understand, because they're so specialised and there's not a lot of them. So I was (...) quite worked up when I went. She [genetic counsellor] did her best to help (...) understand your risk and what are the chances you might get a tumour in the breast, but it's not as easy as you might think. It's not like they are telling you you've got a broken leg that needs a plaster (...) when it's genes, it's a different matter. You don't understand for a start, well I couldn't really understand it all, and you are going in completely blind, knowing absolutely nothing except what's happened to your family. Genetics, well it's not the type of thing the man in the street is going to know much about is it? So I just thought, "who am I to disagree with what they're saying"?

It was thus evident those who were able to speak about genetics were constructed as experts who knew the truth about breast/ovarian cancer. Unanswered questions as to why people get cancer are addressed in the genetics discourse. However, the specialised and scientific nature of genetics means genetic information is a particular

type of information, the acquisition of which makes people dependent on and maintains the dominance of medicine as the expert authority.

From a Foucauldian perspective, genetics can be understood as a particular form of medical specialism which supports biopower (Lemke, 2004). Increasing specialism and rapid advancements in genetic technology has resulted in “overgenetization” (Willis, 2005, p. 152) and has cemented the importance and value attached to genetic information (Helén, 2005; Paul et al., 2014). In Western society, genetics is hailed as a new frontier and a triumph of medical advancement (Finkler, 2000). A Foucauldian interpretation accordingly allowed genetics to be understood as an emergent discourse which maintains and reinforces medical prestige and power. The language of genetics is important because it reinforces how specialised genetic information is, thereby potentially isolating non-experts, such as the people undergoing testing. Jacqui discussed her isolation from the discourse thus:

The genetics woman [counsellor] was really good (...) but there’s just so much to take in. She went back over all the research and the statistics and tried to put my risk into understandable language but I still couldn’t quite take it all in. (...). Every time they asked “do you have any questions?” I think I said something like “no, no, you’ve explained everything really well”, or words to that effect (...) you don’t like to ask too many questions, they’re the specialists after all, they’re the ones who know what they’re talking about.

The participants’ stories show how discourse has the potential to both enable and exclude (O’Farrell, 2007). Foucault (1973) argued medical discourse was supported by an increasingly sophisticated language which conferred a growing knowledge of facts and truths about the human body. On the one hand, this is enabling because knowledge of cancer risk allows individuals to take action to reduce risk (Paul et al., 2014). On the other, genetic information is extremely complex (Braithwaite et al., 2006; Hoskins et al., 2012) and requires knowledge of genetics and statistics (Case et al., 2005) which is out with the scope of most people’s understanding (Ilkilic, 2009; Tamir, 2010) and hence is largely unavailable to them (Tonkiss, 2012). Like Susan and

Jacqui, Ann also revealed the challenge high risk women face when attempting to locate themselves within such a discourse;

The first few meetings at the hospital [to discuss management options] seemed unreal. Looking back I think I sleep-walked through them. Ken had to take notes (...) because I could never remember the discussions. Even what I did manage to take in, it was not easy, not straightforward. I don't think I am particularly thick but some of it was a struggle to understand. There is an enormous amount of information to be given and a lot of it is very complicated and you are trying to deal with it when all you can think of is, am I going to die, is this it?

The analysis suggested the voices of those at risk may be lessened because the expert language of the discourse authorised certain speakers and excluded others (Tonkiss, 2012). Whilst medical discourse defines HBOC and prescribes its management, the discourse of specialism which underpins genetic medicine conceals the persisting uncertainty about why people get cancer (Löwy, 2010) and that the information on which management guidelines are based is incomplete (NICE, 2013), temporary and open to multiple interpretations (Timmermans & Buchbinder, 2012).

Applying a Foucauldian analysis then suggested breast/ovarian cancer is an object of interest in medical discourse which acquired different meanings in different historical contexts. Accordingly, although an organic disease, the construct of breast/ovarian cancer is itself fluid and understandings of it are dependent upon what is considered rational and 'the truth' at a given point in time. Somewhat ironically, as genetic technology continues to advance and new genetic knowledge emerges, inevitably risk estimations for some people will prove to be inaccurate and require revision (Lock & Nguyen, 2010). Moreover, advancements in less mutilating techniques such as MRI screening are likely to offer survival rates comparable to RRS hence RRS may become less 'routine' (Kurian et al., 2010). Despite this, women are undergoing irreversible, life-changing surgery; such is the strength of the current medical discourse. However, as this study shows, resistance to the dominant discourse is possible, because as

Foucault contended, knowledge and 'the truth' are unstable constructs and hence are always open to challenge.

The issue here is not whether genetic information is true or false/right or wrong, and there is no question owning a BRCA1/2 mutation increases the likelihood of developing cancer in high risk populations. What the analysis in this study suggests is that the construction of genetic risk as 'the truth' about why people develop breast/ovarian cancer and the representation of those who are able to speak about genetics as experts who can accurately read, interpret and remedy the body, sustains a discourse which may exclude the very people it seeks to assist. The issue of risk appears critical. The risk discourse has become significant because medicine was able to utilise the emergent genetics discourse to maintain dominance. A space was created within the medical discourse to encompass the risk of cancer as another way of controlling the body, enabled through genetic testing.

This in turn highlights another effect of discourse evident in the participants' stories: the conflation of risk with disease. The next section presents an analysis of the effects of genetics, risk and cancer discourses which revealed a discursive matrix in which cancer risk was located in women's bodies, generating fear and subjecting high risk women to medical intervention to control the deadly inheritance.

Genetics, risk and the cancer discourse

It was apparent being identified as owning a genetic marker for breast/ovarian cancer was a traumatic and frightening event for the participants and their families. Although Susan, Rosie, Ann, Pauline, Mary nor Jacqui had a personal cancer diagnosis, their stories revealed epiphany moments around the realisation their relative's cancer might be hereditary hence they and their own children might come to be afflicted with the disease. Analysis of their stories revealed the effects of the medical/genetics discourse

which created hegemonic constructions of risk and influenced how risk status was perceived and negotiated.

From a Foucauldian perspective, discourses around and about cancer construct and present cancer in particular ways and are supported discursively in the ways cancer is spoken about. Specifically, discursive practices alert people to the seriousness of cancer through the language employed and the cultural connotations attached to that language. Sontag's (1979) seminal work exposed how military metaphors constructed understanding and experience of cancer and presented the body as under attack from a deadly invader, and such metaphors remain prominent in the cancer discourse (Clarke & Everest, 2006; Cobb & Starr, 2012; Grant & Hundley, 2008; Haines et al., 2010; Reisfield & Wilson, 2004). Analysis of the participants' stories suggested this militaristic discourse has extended to the discourse on cancer risk. Jacqui described an online discussion in which she had taken part when she was considering RRS:

When I was first going through this thing (...) deciding whether to have it [surgery] or not, I looked on the computer quite a bit (...) research it myself. I remember going on one of the self-help [web]sites (...) but everyone seemed to be having the surgery done. I couldn't see anyone who was not having it [surgery]. (...). There were some who were struggling [with the decision] but most seemed to want it [surgery] asap and couldn't wait to get on with it. Someone described their boobs as ticking time bombs and everyone agreed, it was, yeah, how they felt too, having them off was the best way to fight it (...) they felt different about their bodies now I suppose. You feel out on a limb really, is my decision really so strange? It was like, feeling like a coward, running away and not facing up to it.

Here we see how Jacqui has constructed herself as a coward as she has been unable to accept RRS to fight back against the threat of cancer. Being cowardly and 'running away' by not accepting surgery contrasts with the heroic battler who fights to win the war on cancer so frequently depicted in cancer discourse (Davis, 2008; Sulik, 2012). This excerpt also shows how high risk women's breasts were talked about as 'ticking time bombs', the suggestion being their breasts harboured a deadly threat which could devastate at any moment. The use of the term 'ticking time bombs' clearly articulates

the life-changing and confronting impact genetic information may have on women and it is a phrase frequently encountered in research exploring BRCA1/2 carriers experiences (for example see DiMillo et al., 2013; Grubs et al., 2014; Hamilton, 2009; Karlan & McIntosh, 2007). Rosie also referred to her breasts as 'time bombs' when she said;

(...) when mine [genetic test] came back positive, I was just totally in shock. I think I had persuaded myself I'd be okay, you know, negative (...) strange logic really but I was thinking because my mum, aunt and sister all had it [cancer], then maybe the chances were the gene had skipped me. They say one in three get cancer then our three had already been used up. (...) So to say I was devastated was an understatement. It literally took the legs from under me. When the specialist tells you you are really high risk of getting cancer, it's really bloody awful. You go from being a normal person to this, well, like going from being normal to having these time bombs attached to your chest. And there's no way of knowing when they are going to go off (...) like you are sitting waiting on something bad to happen but you have no idea when. (...). I suppose you worry more because, well it's a fear of the unknown. It's not like having arthritis or something like a skin condition. (...) [be]cause of course you still look the same on the outside but it's what's happening inside (...) what might be growing in there.

These excerpts illuminate how cancer risk, as revealed through genetic testing, disrupted the previously held sense of self as 'normal' and instead constructed the body as defective and dangerous. Although none of the participants had cancer, their stories revealed the intensity of the emotional reaction to being identified as high risk of developing breast/ovarian cancer and confirmed the presence of significant levels of distress and anxiety which accompany this type of genetic information (DiMillo et al., 2013; McLamara, 2013; Samson et al., 2014). Mary also highlighted how women's breasts come to be considered deadly as a result of carrying a BRCA1/2 mutation. In this excerpt, Mary discusses an online conversation on a breast cancer self-help forum which she had taken part in shortly after her genetic test result:

Some of the women had already had cancer in one breast and had the other one off [preventatively]. They all said if they'd known before and had them off sooner they wouldn't have got cancer. One of them said I had to get rid of my killer boobs, not just for me but for my family (...) to stay alive for the sake of my kids. There was not really anything being said you might not get cancer (...) it was all very definite it would happen, it was when, not if.

Here, cancer was constructed as residing in women's "killer" breasts, the removal of which was necessary to ensure survival. Thus although BRCA1/2 mutation carriers are disease-free, their lives are effectively at risk because of the tendency to treat genetic risk as a disease in itself (Conrad, 2007). Risk is medicalised and represented as an empirical calculation and an objective marker which can be modified by engaging with risk reducing interventions such as surgery. Moreover, although genetic risks are based on models of probability, they are constructed socially as certainties (Finkler, 2000). This was clearly articulated by Pauline who explained:

Although my mum and granny had both had breast cancer, it was a major shock when Sarah was diagnosed because she seemed quite young to get it. I don't remember my granny much but my mum was in her late fifties when she got caught [diagnosed with cancer] which we were told wasn't unusual really (...) but Sarah got her's before the menopause which they [doctors] said was more unusual and with mum and gran (...) that's the first we heard about familial cancer. We knew it [cancer] ran in families so the chances are someone would get it but we didn't know about genes (...) cancer could spread from the mother to the daughter through the gene.

Pauline clearly located risk within genes and equated genes with disease. Thus, the risk of disease as determined by the presence of the genetic marker was equated with disease itself. Notably, deviations in DNA are labelled as 'mutations', 'faults' and 'defects' making the genetics discourse a "discourse of deficiency" (Gottweis, 1997, p. 65) fostering a dependence on medicine to 'repair' broken bodies (Conrad, 1999, 2005; Lemke, 2004). This was cogently articulated by Jacqui:

When I got the letter, I just fell apart (...) it felt like the old me was gone and replaced with another faulty version. I ended up going to my GP. (...) as I just couldn't function. I couldn't speak to anyone without breaking down. I shocked myself at how badly I took it (...) I thought I was stronger.

It was clear Jacqui was devastated by her genetic test result to the point of her being unable to function and "falling apart". Like Rosie whose genetic status transformed her from 'normal' to a 'time bomb', Jacqui reconstructed herself as 'faulty', and was also forced to call into question aspects of self which were previously certain, in this case her strength of character, despite having no disease. Samson et al. (2014) asserted

that genetics and risk discourses not only affected a person's sense of the physical body, but also affected the sense of self, altering a person's biography and creating a re-establishment of the self as 'faulty'. They also contended that these individuals had to re-negotiate a life transition as BRCA1/2 mutation carriers to actively create and adapt to new life realities.

Genetics, risk and cancer discourses coalesce to construct a woman's body as a site of risk and move cancer from the clinical arena into everyday life (Davis, 2008). The conflation of risk with disease causes existential implications which require BRCA1/2 mutation carriers to learn to live under Damocles' sword (DiMillo et al., 2013; Samerski, 2006). Ann described her feelings following her mutation-positive test result:

I remember being in a daze for ages, days and days, then waking up one day and thinking 'where do I go from here, what do I actually do with this?' It was all just so depressing really, so in-your-face, no escaping it and no way of putting it out of your mind. I know this sounds really dramatic, but it was like getting a death sentence.

Here, the notion of risk-as-disease is exemplified through Ann's depiction of carrying a BRCA1/2 mutation as comparable to getting a death sentence. In the same vein, Susan revealed how she initially equated her genetic test result with an impending terminal event:

The day we got the results is imprinted on my brain for ever. I remember feeling, "oh well, that's it then, that's me fekked [done for]". I did cry when I thought about Emma. How am I going to tell her her mum's probably going to get cancer and die? How do you tell your wee girl you might not be there to see her grow up? It was the worst possible thing (...) it just felt really bleak (...) you know, doom and gloom, finding out you could die young.

This conflation of risk with disease goes some way to explaining the women's and their families' fearful reactions to a positive BRCA1/2 mutation test result. Rosie, Susan, Pauline, Ann, Jacqui and Mary did not have cancer, yet in keeping with Samson et al. (2014) and DiMillo et al. (2013) their BRCA1/2 mutation status meant they experienced a raft of emotions including fear, anger, anxiety which left them feeling frightened, vulnerable and with a palpable fear of dying. It was thus evident owning a BRCA1/2

mutation induced feelings similar to being diagnosed with cancer. From a Foucauldian stance, this occurs because of the power of dominant discourses. The contemporary genetics/risk discourse on breast/ovarian cancer has reconstructed breast/ovarian cancer from something which happened *to* the body to something which happens *because* of the body. Whereas previously cancer was seen to occur as a result of external factors, the increasing organisation of medicine around genetic causes of cancer supports a discourse which situates the cause of cancer as residing primarily within the body. Hence BRCA1/2 mutations take on the status of cancer: it is this conflation between risk and disease/death which makes genetic information potentially devastating.

Evidence of the equating of risk with disease was also apparent through the depiction of those who tested mutation-negative as not at risk of cancer. Susan somewhat derisively described her aunt's relief about her cousins' negative test results:

My aunty Helen was over the moon Elaine and Claire's were okay. I can understand they were all really relieved, to know it [cancer] wasn't going to happen to them, they were in the clear (...) but it felt like they were so busy celebrating I got a bit forgotten about. And mum was really happy about Rhona [Susan's younger sister], saying well at least Rhona's going to be okay and she only needed to worry about me. Helen being all "yes, we're alright, so glad we had it done, what a relief, everything's rosy in our garden", which was a bit off I thought really, considering mine [test result].

Susan's story confirms that those who did not carry a BRCA1/2 mutation were considered 'safe' and perceived as being insusceptible to the disease. Rosie also believed her sister and cousin were not at risk of cancer because test results had been mutation-negative:

But looking back, as well as being devastated, I was also a bit peeved, well angry really it was me, the "why me?" They [sister and mother] were obviously really happy she [sister] was not at risk, and I was for her too, really, but it was ironic in a way (...) Julie [sister] was the one who wanted it [testing] so much and she was getting away scot-free. She was going to be okay and I was the one getting the bombshell. I admit I did feel sorry for myself and my family. It was hard to look at Julie. I really did feel happy for her but it did change things if I'm honest. I didn't like her feeling sorry for me and I think she found it hard to be happy

around me. It's a bit like someone you getting pregnant when your sister can't (...) it's the elephant in the room.

Likewise, Jacqui discussed her sister Joanne's mutation-negative result thus:

When Joanne got the all clear, I was really chuffed for her. She's the baby of the family so I really did want everything to be okay for her. The three of us are really close, especially after losing both mum and dad, but at the same time I did feel a bit resentful she got good news and I didn't. (...) Beth [affected sister] genuinely thought the testing and the results were a great thing. Joanne was in the clear and I was now able to do something about it. By then I was outwardly more calm but I didn't feel it inside. I felt I had to stay positive for everyone else so it did drive a bit of a wedge between us if I'm honest.

The labelling of those who tested negative for a gene fault as 'not at risk' or 'in the clear' conflicts with empirical risk calculations which confer the general population risk for developing breast/ovarian cancer to mutation-negative women (NICE, 2013). Medical risk calculations relate to high risk women with BRCA1/2 mutations, but as many as 1 in 8 women will develop breast cancer regardless (AIHW, 2012). A Foucauldian interpretation suggests this reflects the contemporary genetics discourse as the truth about why people get cancer. What is hidden in this discourse is that non BRCA1/2 mutation carriers may still develop cancer, or indeed, that BRCA1/2 mutation carriers might not.

The dominance of the genetics discourse reflects what Conrad (2001, p. 225) referred to as "genetic optimism": a belief that by studying genetic material causes for disease and ill-health can be identified, manipulated and rectified. To a degree conflicting discourses are present because contemporary cancer discourse is paradoxically one of fear and reassurance (Crabb, 2006). On the one hand, the equating of genetic risk with disease means owning a BRCA1/2 mutation is considered devastating and deadly. On the other, cancer/risk is an invader to be bravely battled against and people can win the war on cancer. This means cancer is simultaneously presented as being deadly yet survivable if the afflicted individual takes appropriate steps to deal with the problem. The following discussion explores how dominant discourses coalesce to translate

beliefs about cancer risk into health actions through the operation of disciplinary power. Power relationships enacted through discourse show the subtle ways women are regulated through normalising practices in relation to HBOC but also reveal how women negotiate, confront and resist power.

Disciplinary power and cancer surveillance

In the previous sections, interpreting the stories of Rosie, Mary, Ann, Pauline, Susan and Jacqui through a Foucauldian lens illuminated a number of discursive practices which maintained the dominance of medical authority, namely genetics as ‘the truth’ about breast/ovarian cancer, the conflation of risk with disease and medicine’s ability to expertly read and attend to risky bodies. In particular, Foucault’s concept of disciplinary power was useful in understanding genetics as a technique of biopower which targeted individual bodies in the quest to reduce cancer risk.

The analysis of the participants’ stories revealed genetic testing was generally considered to be the most sensible action or indeed the *only* action to take when confronted with the threat of cancer. Once a BRCA1/2 mutation was suspected or identified within the family, it was taken-for-granted and expected that family members would undergo genetic testing. Jacqui and Pauline had accepted testing without hesitation, although interestingly both commented on the seeming simplicity with which their affected relatives had undergone testing which may have influenced their initial decision making. Jacqui’s sister was identified as carrying a BRCA1 mutation whilst receiving treatment for breast cancer and her family’s main concerns had lain with her sister’s health therefore when testing was offered to Jacqui, she accepted without question:

When they offered us testing, it seemed like the most obvious thing to do. I don’t think I really thought about the implications. It’s like you are caught up in the emotion (...) you don’t really question, you just do. Unfortunately it soon struck me it was a bigger and more important

decision than I first thought (...) the implications. I only thought about it after I got the letter with the results, which seems crazy now.

Similarly, Pauline was also at the outset keen for testing to determine her personal risk of cancer and believed knowledge of her genetic status would offer control over her future health:

So there was never any issue of me not having it [genetic testing]. I felt it was really important to know if I had it [gene fault] so I could do something if I did. Looking back, I just never appreciated what it meant, what it involved (...) it was all new to us. I thought it would be a simple test then, well I would do what needed to be done, if it came back positive. But of course, life's not like that is it? Once you are on the rollercoaster it's hard to get off.

Disciplinary power trains and controls individuals to think and act in similar ways by defining 'the norm' and constructing deviation from the norm as abnormal or aberrant (Lilja & Vinthagen, 2014). In keeping with Armstrong's (2007) contention, disciplinary power was reasoned to be operating through the genetics discourse through the positioning of genetic testing as the norm; a straightforward, routine procedure which was the only sensible action for women at risk of cancer. Foucault (1977) argued the nature of disciplinary power was such that bodies were required to be docile and manipulable in order for non-coercive controlling techniques to be effective. A docile body is one that "may be subjected, used, transformed, and improved" (Foucault, 1977, p. 136), making the body a site of regulation and both an object and target of power (Turner, 2008). Observation, surveillance and control are key components in creating docile bodies (Forbat, Maguire, McCann, Illingworth & Kearney, 2009) therefore disciplinary power works to recruit those at risk of cancer into surveillance strategies aimed at maximising the body potential by attempting to control cancer risk. Accordingly, a Foucauldian interpretation contended knowledge of genetic status was not the end point; rather it permitted technologies to be performed on the docile body. For disciplinary power to achieve its objective, that is transformation of the risky body to the lower risk/improved body, knowledge of genetic status was the first step in allowing

'something to be done', namely RRS, to render the body safe. Here, Ann recounts her sister's advice:

(...) at least now we know what's wrong, they [medicine] can do something about it. At least there's stuff they can do to sort it. I didn't have the chance at first but you have the chance to get yourself sorted. You can beat it [cancer] before it even begins.

Ann's sister had breast cancer and had undergone mastectomy, contralateral prophylactic mastectomy and prophylactic bilateral salpingo-oophorectomy, and whilst it was not explicitly articulated 'what could be done', it was clear Ann's sister believed RRS would transform Ann's body from risky to safe as Ann could 'beat' cancer before it developed.

In this study, a Foucauldian interpretation suggested high risk women's bodies may be rendered docile in medical discourse which convincingly constructs cancer surveillance and risk reducing interventions as strategies which control future health. Presymptomatic genetic testing for HBOC is predicated on the assumption it facilitates a comprehensive surveillance strategy and effective interventions which reduce risk and save lives (Esplen & Bleiker, 2015; Schwartz et al., 2012). Such assumptions are endorsed through the official HBOC discourse as outlined in clinical guidelines such NICE (2013) and Cancer Australia (2011, 2015) which make recommendations for the management of BRCA1/2 mutation carriers. However, applying a Foucauldian critique illuminated notions of surveillance which were particularly relevant to contemporary understandings of breast/ovarian cancer because unlike other forms of cancer surveillance such as mammography which detect the signs of disease, genetic testing is a form of medical surveillance which scrutinises people for the *potential* for disease.

An effect of genetic testing is that it allows women who test positive for BRCA1/2 mutations to be marked as "genetically at risk" (Novas & Rose, 2000, p. 486) and constructed as "asymptomatically ill" (Billings et al., 1992, p. 476), "pre-disease"

patients (Kreiner & Hunt, 2014, p. 870) and “patients-in-waiting” (Timmermans & Buchbinder, 2010, p. 409). Accordingly, genetic testing can be understood as a modern form of surveillance for the asymptotically ill. For Foucault (1973), surveillance was a feature of modern medicine which expanded the medical gaze to include not only the sick, but the potentially sick. The shift towards surveillance in medicine was supported by increasing technological advancements, or a “technology assisted medical gaze” (Griffiths et al., 2010, p. 7) which permitted the internal body as well as the external to be visualised, recorded and assessed.

Genetic testing further extends the scope of surveillance down to the cellular level (Armstrong, Michie, & Marteau, 1998) and offers what Hoffman (2011) described as a multiplicity of gazes which opened more people up to scrutiny and extended disciplinary power. In this study, a further effect of disciplinary power was that even those who initially resisted genetic testing were persuaded to submit to the medical gaze, as Mary explained:

But I was worried about what it [genetic testing] would mean. My youngest is only 16 and she might need a mortgage one day. They said it shouldn't affect it but you never know. (...). It just seemed to me to be asking for trouble. It was all a bit up in the air (...) the doctors couldn't really answer the questions I had. But in the end I let myself get talked into it. They [friends and family] persuaded me it was the best thing, and in reality, part of me was really keeping everything crossed it would come back normal.

Applying Foucault's concept of disciplinary power proposes genetic testing is a surveillance practice which creates rhetorical modes of understanding and exposition which discipline risky bodies in support of the medical discourse for managing cancer risk. Participation in cancer surveillance is a socially mandated behaviour presented as a rational act; therefore placing one's body under surveillance is an expression of social responsibility and rationality (Willis, 2005). Disciplinary power dominates when groups of individuals such as high risk women, are subjected to the same interventions, practices and outcomes irrespective of individual needs (McCarthy, 2005). Genetic

testing appears to be a common-sense response to risk but from a Foucauldian stance is technique of power which controls bodies in the interests of the specialism and contributes to the regulation and government of individuals at risk of cancer (Lemke, 2004), extending the authority of medicine over people with no disease. This enables disciplinary power to be discreet yet ubiquitous and provides the mechanism which persuades people of the need to surrender their bodies to the medical gaze and conform to normalising strategies as outlined by medicine (Armstrong, 2007; Crabb, 2006; Happe, 2006). Rosie also described how she came under the medical gaze:

I was always a bit uneasy going for the testing but I kind of felt I had to do it for Tom and Neil, plus there was, well he [husband] sort of assumed I'd go, he didn't even question it. It was just assumed I'd go. No-one really forces you, but it's there anyway (...) a pressure because, well it seems like you should go and (...) have it done. Also, since mum had gone and got it done for us, it seemed a bit pathetic for me not to go.

Rosie succinctly exposed the non-coercive, persuasive nature of disciplinary power: Rosie has not been 'forced' into testing but none-the-less felt she had to be tested and clearly her loved ones also assumed she would undergo testing. Although not explicitly stated, the need to discipline the body and partake in surveillance permeates through discourse and is taken up as the desired response when faced with cancer risk. This was further evidenced through references to family rifts and those who refused testing being rejected within the family unit. Rosie's affected sister (Sheena) had refused testing which had led to bad feeling and a falling out between her siblings:

When we found out Sheena wasn't going to have the [genetic] testing, there was a lot of drama, especially Julie [sister] and her man [husband], they were not happy bunnies!. They both flipped out because they wanted to know what were the chances of the rest of us having it, or spreading it on to our kids. They were also on at me to put pressure on her to have it done which really upset me. (...) But Sheena was adamant she wasn't getting it done so she stuck to her guns. They fell out about it in the end (...) Julie stopped visiting Sheena because she was so angry with her.

Rosie's sister's refusal of genetic testing may be understood as resistance to disciplinary power, or a refusal to take part in self-disciplining practices (Lilja & Vinthagen, 2014). The impact of this resistance was significant because in the case of

HBOC it extended to others in the family who may be denied access to the medical gaze to determine their own risk of cancer, leading to anger and upset. Genetic testing produces new knowledge about individuals and functions as a “politics of truth” (Lemke, 2002, p. 8) hence those who resist genetic testing are especially problematic because others are denied the chance to uncover the ‘truth’ about their genetics and hence their own bodies. Ann’s cousin Shona had also refused testing, which led to family discord and attempts at emotional blackmail to persuade her otherwise:

She [cousin] got offered it even though her mum was dead because they were doing research on the cancer genes and her family history was so strong. The genetics people said they might not find anything but would still do [test] her and keep it on file for later. Shona said she didn’t see the point and it would do more harm than good (...). They [family] all said she had to go and find out. She’d be mad not to grab this chance to find out with both hands and then we’d all know who needed what. My Uncle Stuart even said it was an insult to Jean’s [deceased aunt] memory as Shona had the chance to do something to avoid what happened to her mum. Shona was really angry at her dad, they didn’t speak for ages.

In this case, refusal of genetic testing was perceived as unacceptable because it prevented the revelation of knowledge which could avert cancer and ultimately death. Resistance to testing consequently exposed the presence of disciplinary power in genetic testing because it challenged the mandate to take part in cancer surveillance and made visible other positions which were available (not being tested) but not desirable. The above excerpt was also interesting in that it revealed what was otherwise hidden in surveillance discourse, namely the tension between docility and agency and the risks of surveillance.

Viera (2011) contends surveillance strategies for pre-disease conditions only make sense when certain conditions met: the measures must have discriminating ability, that is, those identified as pre-disease must be significantly more likely to develop the disease than those not; there must be an effective intervention which prevents or reduces the likelihood of disease and the benefits of the intervention must outweigh the risks. This may in part explain why Rosie, Mary, Ann, Pauline, Susan and Jacqui

submitted to genetic surveillance but said no to RRS. The analysis suggested that for the participants in this study, Viera's (2011) third condition was not met hence resistance to disciplinary power was possible because the risks of the intervention for the pre-disease condition, namely RRS, were too great.

Lilja & Vinthagen (2014) argued resistance to disciplinary power can entail a form of reversed power in which the same technologies of power are employed but in ways which open up spaces for individuals to make their own decisions. This is in keeping with Foucault's (1980, 1982) stance that power is productive as well as repressive because power allows things to happen and permits positive transformation through the negotiation of power relations (Allen, 2008). From this perspective, cancer surveillance strategies can be understood as providing a means through which high risk women renegotiate power relations in medicine by accepting interventions which allow them to self-regulate their risky bodies in ways which make sense to them. Although Rosie, Mary, Ann, Pauline, Jacqui and Susan discussed many challenges thrown up by their genetic test result, surveillance strategies, in particular mammography appeared to offer some promise of control over their future health. All discussed personal or others' beliefs mammographic surveillance offered an opportunity to detect early cancers which could then be successfully managed through medical intervention. Jacqui explained:

(...) with my risk, going for the scans, the mammograms, well that's really important now you know, because then if there's anything starting, a tumour or even changes in the breast which maybe could turn cancerous (...) things like changes can be seen on the scans before it turns into cancer.

Here Jacqui acknowledged her risk of cancer as high and appeared somewhat reassured that mammographic surveillance was able to detect precancerous lesions as well as early cancers. High risk women may be reassured by surveillance because the body is under close observation (Hamilton, Williams, Skirton & Bowers, 2009; Kurian et al., 2005) and may therefore prefer to take part in surveillance (Griffiths et al., 2010;

Sabatino et al., 2004) despite limited evidence on the safety and efficacy of breast surveillance in high risk women (de Gonzalez, et al., 2009). Rosie also articulated a belief in the value of mammographic surveillance:

I know I should have scans as well but I don't go anymore. (...) I went the first few times but it was horrible. I know it's stupid and deep down I should go and I've been on and off about going, although I do really know I should go. But I am really going to try and go back. I should then if it does happen [cancer] at least they can catch it early (...) then I would take it [surgery], if I got cancer.

Here it can be understood that Rosie was in a process of renegotiating her position in medical discourse: despite finding mammography deeply unpleasant and initially withdrawing from it, her belief in the value of surveillance meant she was willing to resume participation. Likewise, although Pauline voiced some doubts, she was none-the-less in favour of surveillance:

Some people say cancer is either in you or it's not. I read on a web site about one woman like me, BRCA2 positive and not having the surgery. (...) She also said she stopped having any tests or scans because they were making her so anxious she felt the stress would bring on cancer. I think there is some truth, maybe but even still I am going for the mammos [mammograms] so they can catch it early. But not the ovary one as my risk is quite low and it [screening] doesn't really work for ovary cancer anyway.

Intensive surveillance may enable individuals to renegotiate power in the medical encounter by having their concerns listened to and acted upon (Forbat et al., 2009). Hence surveillance is both a technique of power and empowerment because taking part in surveillance is a means through which high risk women can have their risky bodies monitored and protected by medical intervention should a future cancer develop. This was evidenced across the participants' stories through repeated intonations that 'early detection saves lives'. Like Pauline, Jacqui, Rosie and Ann, Mary and Susan also viewed surveillance as a means of protection rather than control:

Living with this [gene fault], well it's something you've got to contend with I suppose. We are lucky in this county we get the NHS [National Health Service] and the mammograms with it, which means I might not get cancer at all (...) so I go and keep everything crossed it [screening] stops me getting it [breast cancer]. It's [having mammograms] something I can do to help myself. (Mary)

I just think, to lose your breasts and ovaries for something which might or might not happen? I am superstitious and I think, if it's going to happen, it's going to happen (...) if you are so high risk, then it's probably going to happen anyway. So I have opted to have screening so I get checked out more frequently so if anything happens it will get picked up quicker and (...) chances are it will still be able to be cured.
(Susan)

Again this reinforces Foucault's position that power is not necessarily repressive but always contingent, creating the conditions through which individuals re-position themselves in medical encounters as holding power and directing medicine to attend to their bodies as required (Forbat et al., 2009). Although Rosie, Mary, Ann, Pauline, Jacqui and Susan said no to RRS, they renegotiated power through an acceptance of mammographic surveillance as a means of dealing with cancer risk and potentially securing future health.

To sum, this section explored how 'the truth' about hereditary breast/ovarian cancer and RRS came to be and how the medical discourse came to dominate. From a Foucauldian stance, the 'truth' about familial breast/ovarian cancer and how it should be managed cannot be known as it cannot exist. What does exist, and what has been demonstrated in this analysis, are the conditions and discourses which prevail at any given time and make possible claims about familial breast/ovarian cancer and its management to be made. The interpretation offered contended power operated through the HBOC discourse because high risk women were persuaded of the sensibility of certain ways of being and acting to avoid cancer and prolong life. However, as Foucault claimed, dominant discourses are effective in creating a range of subject positions because the creation of an ideal subject position invariably creates other subject positions at odds with the ideal, creating the space through which resistance to the dominant medical pathway for HBOC is possible. The next section applies a Feminist analysis to the participants' stories and illuminates ways in which Susan, Rosie, Jacqui, Ann, Mary and Pauline sought to make sense of their

experiences and have their voices heard. A focus on their resistance to the medical pathway for dealing with breast/ovarian cancer risk extends the interpretations presented in the previous analytic sections in light of the convergence between the three literary theories utilised, as discussed in Chapter 4.

An interpretation through the lens of Feminist Literary Theory

Feminist literary theory poses questions relating to power relationships in societies to gain understanding of female social reality (Allen, 2014). Key to this is the argument all human, social relations are gendered; therefore how women have been constructed and represented in society reflects power struggles at the individual and societal level. From a feminist perspective, female characteristics are socially constructed rather than biologically determined. For example, men are constructed as strong, dispassionate and career-orientated whereas women are constructed as weaker, emotionally labile and nurturing (Mikkola, 2012). While differences between males and females are acknowledged, the extent to which these differences are innate or socially constructed is problematised through the lens of feminist literary theory. Analysis of how the female role, femininity and womanhood are socially constructed allows an exploration of the dynamics of gender and power relations which may subordinate women.

A feminist critique added a valuable perspective to this study as it concerned an important female issue: hereditary breast/ovarian cancer. Although male breast cancer does exist and men can pass BRCA1/2 gene mutations to their children, women at risk of HBOC face exacting challenges because norms of feminine embodiment are fundamentally tied to female breasts hence breast loss is especially confronting for women (Ehlers, 2012). Additionally, the unique positioning of women as the gatekeepers of family health in Western society (Acero, 2012; Warner & Procaccino, 2004) exaggerates the moral component of health decision making and adds another

layer of complexity to the HBOC journey because women are also obliged to protect others from the threat of cancer.

In this section, a feminist critique served as an analytical tool through which the participants' stories were read by the researcher for ways in which Susan, Rosie, Jacqui, Ann, Mary and Pauline sought to interpret, negotiate and make sense of their individual circumstances. There was a focus on how their personal decisions to say no to surgery were not fully understood within the broader social and cultural frameworks which endorsed or denounced the decision to refuse RRS. The rejection of the advice and cancer pathway offered by the official medical discourse on HBOC, and a decision which is argued to be 'anti-health' in the context of Western medical discourse, confirmed other discourses existed. The participants' personal journeys and the ability to say no served as a potent signifier of competing discourses and multiple, conflicting ideologies which defined, described and directed HBOC and its management and underscored the vexing reality of women who found themselves living with this risk.

The feminist concept of resistance provided the key focus of this analytic section. To reiterate, resistance is understood as a means of fighting back against forms of oppression and dominant ways of thinking which support the subordination of women (Gotfrit, 1991). Utilising a feminist critique aims to problematise and make visible the workings of hegemonic discourses which may oppress women by reframing the body at risk of breast/ovarian cancer as a potential site of resistance to such dominating practices. A feminist perspective thus highlights resistance as a potential practice of empowerment which challenges taken-for-granted assumptions which may oppress women through an illumination of the conflict and contradictions present in everyday discourses (Allen, 2011). Talbot, Bibace, Bokhour and Bamberg (1996) posited women's narratives function as forms of resistance to master narratives and discourses which seek to hold individuals to culturally driven standards which define acceptable

behaviours, in this case, the dominant medical discourse. In this study, resistance was a means through which high risk women became aware of the competing and conflicting discourses which surround HBOC and its management which led to the creation of alternative discourses which made sense of their experiences. Application of the feminist concept of resistance was a means through which the analysis connected the women's stories to the prevailing communal folklore on HBOC and highlighted the creation of a private folklore in relation to saying no to RRS.

This section examines the multiple resistances to dominant discourses and ideological practices which were discussed in the previous analytic sections. This means some sections of narrative are referred to again when particularly useful in supporting the analysis. Additionally, owing to the relative paucity of research in this area, it was necessary at times to extrapolate from the wider literature relating to refusing conventional medical treatment.

Many discourses, competing ideologies

The analysis in the previous sections revealed high risk women may be conflicted by competing and contradictory messages on how best to attend to breast/ovarian cancer risk. The dominant medical discourse lays claim to knowledge about the truth of HBOC and how best to manage cancer risk. Being identified as high risk of developing breast/ovarian cancer places a genetic responsibility on high risk women to be active, concerned, patients-in-waiting and take affirmative action in the present to protect themselves and others from the future risk of cancer. Simultaneously, ideologies of femininity and sexuality produce a persuasive discourse on how women and their bodies should be in Western society, a crucial part of which is having two breasts and ovaries.

In the stories of Susan, Rosie, Jacqui, Ann, Mary and Pauline, there was acknowledgement of gendered discourses in Western society and ways in which women were confronted with idealised images of the female body in everyday life, particularly in relation to the female breast. Rosie alluded to this when she said “Everywhere you look it’s all ‘tits ‘n’ ass’ (...) sex sells, doesn’t it?” and Susan acknowledged the prominence of an idealised female image when she explained “they’re all over the place (...) women’s breasts (...) boobs selling cars, Wonderbra adverts, all that sort of stuff. It’s like a constant reminder of what you are giving up”. Susan’s words here highlighted the painful enormity of the decision to forfeit one’s breasts because of risk. In many ways, Rosie, Mary, Ann, Pauline, Susan and Jacqui faced a no-win situation. To attend to cancer risk as defined by the medical discourse results in a number of other risks to self, thereby creating an uneasy tension between the provision of risk reducing strategies which may protect women from cancer but which also strip them of socially mandated essential female characteristics.

It was evident then societal and medical concerns about cancer risk generally and breast/ovarian cancer, in particular, were represented through various discourses and ideologies which surrounded HBOC. Key stakeholders in HBOC discourse include medicine, biotechnology and pharmaceutical industries, the media, patient advocacy groups, academics, scientists and researchers and the public at large, therefore it is not surprising different discourses and their attendant ideologies may conflict as each vies for ascendancy. However, the participants’ stories revealed high risk women can and do demonstrate resistance to such dominant discourses and ideologies. Resistance can be understood as a positive force which exposes the contradictory nature of conflicting ideological stances which burden high risk women with impossible choices. Simply put, in Western society it is unacceptable for high risk women to fail to attend to breast/ovarian cancer risk yet it is also unacceptable to be *breastless*. It is from this very contradiction that resistance emerges and it is resistance itself which

exposes competing ideologies and contradictions in discourse in relation to HBOC which may oppress women.

A feminist interpretation suggested the potential for resistance emerged as high risk women became aware of ways in which dominant ways of thinking conflicted and diffused uncertainty, creating ambivalent and unpleasant experiences. This was summed up expressively by Rosie when she offered her interpretation of making her decision regarding RRS:

Well I say options but (...) I'm not sure of the right word, they're not really options. It's like choosing between two forms of torture. Option one, get them [breasts] off, mutilate your body, option two, get cancer and die. Not much of a choice! (...) then they say "oh well, you know, it's your decision", like they expect you to be able to decide on the back of that? Okay so you'll be a survivor but at what cost? Left half the woman you once were?

Here, Rosie clearly articulated a 'choice but no choice' dilemma. Although it appeared Rosie's autonomy had been promoted, she did not articulate a feeling of freedom or empowerment in making her decision. In cancer risk discourse, individual autonomy and choice are emphasised (Sato, 2012) and decision making around RRS is consistently framed within the context of rational decision making. For example, Fry et al. (2001a, p. 584) noted "cancer worry seems to override a more rational consideration of costs and benefits of (risk reducing) surgery" while Lodder et al. (2002, p. 111) stated "ideally, it should be prevented that high anxiety would impede rationally weighing pros/cons of prophylactic mastectomy". More recently, Zagouri et al. (2013, p. 207) showed little has changed by stating "the decision for prophylactic mastectomy should be evidence driven and rationally guided by genetic testing".

The positioning of high risk women as autonomous decision makers in medical discourse exposes the inherent ideological conflicts and posits medical authority as problematic in the accounts of Susan, Rosie, Jacqui, Ann, Mary and Pauline. Bishop and Yardley (2004) claimed medical expertise was problematic in egalitarian societies

because the positioning of doctor-as-expert gives power over non-experts hence resisting medical authority is regarded as irrational rather than agentic. Knowledge obtained through genetic testing is considered as Zagouri et al. (2013) and other researchers' positions demonstrate, as knowledge which allows an individual to make a rational decision based on knowledge of the 'facts' about one's genetic status. Genetic testing leads to normative expectations on how to respond to risk (Paul et al., 2014) since the underpinning assumption is the consequences of risk are made avoidable (Ilkilic, 2009). The following quotes from three health care practitioners in Witt's (2013, p. 117) study demonstrate how the importance of autonomy is embedded in medicine but also the restricted and narrow discourse within which decision making takes place:

I would be very happy if all my patients who were at risk for ovarian cancer had oophorectomies. I wouldn't want to push oophorectomies on them, but rationally it is the best way to manage that risk, but ultimately it's the woman's own decision.

I mean we are very emphatic that surgery is the thing that we recommend. And that really, you know, if you are in your 40s and certainly if you are over 50, you should be having your ovaries out.

Everyone of us has to die, but I feel very strong that women don't have to die of ovarian cancer. It might [be] easier to have a heart attack.

It is clear from Witt's (2013) study health care practitioners held personal beliefs about what actions high risk women should take based on their positioning as experts who knew the 'best' way to respond to risk. Health care practitioners are socialised within the dominant medical discourse (Martin, 2014). It is therefore not surprising to find ideologies consistent with this discourse namely ideologies of autonomy, self-responsibility for health and surgical intervention for risk. Other influencing contexts within which women make decisions may be acknowledged but are largely relegated over the expert view on what is the best way to respond to risk. Managing cancer and by extension cancer risk, hence presents the potential for ideological conflict (Bishop & Yardley, 2004) because autonomy requires high risk women to be accountable for their own decisions but conflicts with the ideological mandate of medicine as best equipped to deal with the threat to health/life.

From a feminist perspective, ideological conflict bears particularly heavily on women because women are encouraged to take the path of least resistance and comply with societal conventions regardless of personal views, hence true autonomy is rarely available (Meyers, 2010). This was reflected in Rosie's story above and in the words of Jacqui who earlier explained how she was expected to make her own decision but "at the same time, [she] felt they wanted me to do what they wanted, which was to (...) take the surgery". In the same way, Susan acknowledged she was given information so she could make a personal choice but this was set against "being told in the first place [you have a gene fault] makes it seem as if you must have the op[eration], or else what's the point [of testing]?".

These excerpts clearly demonstrated how decision making in response to breast/ovarian cancer risk was contextualised with a discourse of medical hegemony and its accompanying power structures (Szumacher, 2006) which may severely curtail the freedom to choose and restrict autonomy. In research which examined some of the conflicts in obstetric medical decision-making, Abrams (2015) contended women's autonomy was threatened when decision making frameworks which sought primarily to reduce risk were utilised. While such frameworks were purported to actualise the women's autonomy, Abrams (2015) provided a compelling argument this was an illusion because the decisions made by the women were taken entirely within the discourse of medical expertise and the primary necessity to reduce risk. Whilst this was not problematic to women who aligned themselves to the medical discourse, it created normalising standards of behaviour which were problematic to those who resisted the dominant view, such as the participants in this study. Within these contexts, decision making frameworks which outline women's choices in attending to risk conceal the more limiting realities women face (Löwy, 2010).

It is important to acknowledge the requisite to undertake RRS to manage risk is not explicitly articulated in medical encounters and health professionals do not ‘tell’ high risk women what to do to lower cancer risk. In keeping with contemporary approaches to health and social care, shared decision making models are emphasised in clinical guidelines for the care of women at risk of familial breast/ovarian cancer, for example, the NICE (2013) guidelines. Implicit in such models is the belief decision making should take cognisance of what matters most to the patient with judicious use of professional knowledge and status (Greenhalgh, Howick & Maskrey, 2014). However, as Abrams (2015), Martin (2014) and Bishop and Yardley (2004) highlighted, the provision of factual information and advice supports a medical discourse which directs health choices in prescribed ways which may serve to reduce autonomy. In medical consultations, the risk of developing breast/ovarian cancer is calculable and quantifiable, able to be visually displayed in numerical data and in written texts. For example, Jacqui explained how much her risk could be reduced through RRS:

When they show you the statistics, how much surgery lowers the risk (...) my risk was said to be about 60 percent for breast cancer and 50 [percent] for ovarian but surgery would take it down to less than 5 [percent] [for breast cancer] and practically zero for ovary [cancer].

Such statistical calculations suggest risk is able to be defined with certainty and RRS is constructed as offering a dramatic reduction in cancer risk for Jacqui. What is not said in discourse is that these statistics apply to populations and therefore may not be representative of individual risk (Grossi, 2005; Samerski, 2006). Hence whilst high risk women are given ‘choices’ or options with regards to managing risk, the decision to say yes or no to RRS is made within the dominant discourse and culture (Gotfrit, 1991) which in the case of HBOC means attending to risk through surgical intervention.

In this study then, conflict was apparent in the participants’ stories as personal autonomy was promoted but simultaneously challenged by the dominant understanding of RRS as the ‘cure’ for cancer risk. This was evidenced in the participants’ stories

through references to RRS as a 'no-brainer', the obvious and logical action to take when one is identified as high risk of developing cancer. It was, therefore, not unexpected the participants struggled at times to make sense of their decision to say no to surgery and to make their decision understandable to others. Here, Mary explained how others found it difficult to accept her decision to say no to surgery:

It felt like being in a dark tunnel with no light at the end. Even though you are surrounded by people, your friends and family, and all the counsellors and the nurses and doctors and (...) they were all really good, but you still feel so alone because people can't understand (...) and they can't stop giving you their opinion. *Just stop with the bloody opinions* [raised voice], you know what I mean?

This excerpt illustrated how resisting the ideal subject position outlined in medical discourse was an isolating experience for Mary because her decision to say no to surgery was challenged by others who could not comprehend it.

A feminist interpretation posited this was exacerbated through women's subjected positioning in society and the legitimate say others had in determining what was right for high risk women (Szumacher, 2006). The contingent positioning of women means concerned others such as family and friends are likely to advise high risk women to comply with medical convention rather than demonstrate autonomy (Meyers, 2010). The language of choice and autonomy which is integral to breast/ovarian cancer risk discourse is therefore not solely empowering but also serves to constrain because the discourse has already defined the right choice to make in response to risk (Hallowell & Lawton, 2002; Sato, 2012). Ann also explained how her autonomy was severely restricted because her choices dissented to those around her:

(...) it all rests on your feelings, how you feel inside. I want to be worry free, to have a life without the stress of it all but at the same time I don't want the ops. I mean who would? I don't want the pain. I don't want lots of surgery to fix me up again after. If I'm honest, I was worried about what I would be like (...) after. How would I look? Worried I wouldn't look like me anymore. (...) But how can you explain these feelings to those who love you? They just want you to be safe, to protect yourself so they just can't see it (...) why you don't just go for it [surgery]. Eventually you give up trying [to explain].

Ann's concerns about surgery were evident and it was clear she struggled to convey these concerns to loved ones who spoke in support of the medical discourse. Although Ann ultimately said no to RRS, taking this alternate position was problematic as desire to be free from worry conflicted with the risks of surgery. Previous research has identified BRCA1/2 mutation carriers experienced constant conflict between two threatening conditions namely the threat associated with being a mutation carrier and the risks associated with surgery (Dagan & Goldblatt, 2009). On the one hand, RRS offers protection from risk (Guillem et al., 2006; Ingham et al., 2013), freedom from worry (Gopie et al., 2013; Hallowell et al., 2012; Lostumbo et al., 2010) and is therefore the obvious path for high risk women to take. On the other, RRS potentially threatens female embodiment (Ehlers, 2012; Piot-Ziegler et al., 2010) and presents women with a number of negative physical and emotional impacts (Altschuler et al., 2008; Hallowell et al., 2012) and therefore may be understood as a risk in itself (Dagan & Goldblatt, 2009). Consequently, surgical interventions which aim to render the body safe from cancer may fail to mobilise high risk women because power and social relations embedded within discourse may conflict with or contradict personal perceptions of risk (Lock & Nguyen, 2010). Hence, the participants' stories exposed the complex and contingent positioning of high risk women and their bodies in Western society which created the conditions for resistance. This section now focuses on an examination of the multiple resistances which emerged from the stories as the participants sought to negotiate the medical discourse and work out their position to and within it.

Resistance to the risk discourse

A fundamental issue for Rosie, Mary, Ann, Pauline, Susan and Jacqui was negotiating biomedical constructions of risk which created normalising responses on how to attend to the risk of cancer. The analysis suggested risk discourse produced an ideal subject position in which the person at risk of cancer does *whatever it takes* to reduce or avoid risk. The participants' own knowledge and understandings emerged as signs of

resistance to this position, thereby challenging clinically hegemonic representations of how HBOC risk should be managed. Highlighting the incompleteness of biomedical knowledge about breast/ovarian cancer risk created the space to assume an alternate subject position to that offered by the medical discourse. The subtexts of the participants' stories confirmed a fear of cancer which created persuasive arguments in favour of RRS but which failed to account for uncertainty. Susan described attempts to justify her decision to say no to surgery to her mother who felt Susan should accept surgery so she could remain alive for her young daughter:

I said "but mum, even if I get it done, I still might not be here for her, that's life". But she would just start crying again and, so, end of conversation. I think in the end I just decided to take my chances. If they could have given me a guarantee it might have been different. It just seemed so drastic, having all that done, when there's nothing wrong with you (...) and not be able to say it definitely won't happen.

Susan articulated personal understanding of RRS as being a procedure which was unable to completely neither protect women from cancer nor ensure longevity. Her position contrasted with that of her mother and evoked a strong emotional response, the implication of which was refusing surgery was akin to a premature death. Likewise Rosie also demonstrated understanding of the uncertainty inherent in risk discourse in contrast to her significant others:

(...) but I mean even with the surgery, there's no guarantee I won't get it [cancer] but no-one seems to understand. They talk as if you have the (surgery, ...) you will never get it, but you still can. It's not set in stone. There is a good chance you are having it all for nothing, who knows?

Like Susan, Rosie's story highlighted some high risk women express understandings of genetic cancer risk which differ to those in the dominant risk discourse. Susan's story continued as she further problematised dominant constructions of risk:

But the more they tell you the less you felt you actually knew. It's weird [be]cause I thought I was pretty sure at the time. I thought the doctors were sure but the more I found out, you find out no-one's really sure. No-one could tell me what *my* [said with emphasis] risk actually was. I asked straight out if surgery would mean there's no chance of me getting it [breast/ovarian cancer] but they couldn't answer that one. I mean, they didn't know. They don't really know why [cancer develops]. So you can go ahead with it [surgery] and you still might get it [cancer].

These excerpts confirmed how Susan and Rosie were conflicted as they came to understand knowledge of genetic status failed to deliver the promise of certainty alluded to in the risk discourse, namely RRS as protection against cancer. Their stories also revealed suggested there was an acceptance that medical knowledge was incomplete, uncertain and changeable: Rosie described genetic information as not being 'set in stone' and Susan discussed her doctor's inability to address all her areas of concern or explain why people get cancer. Likewise Pauline acknowledged the uncertainty in risk discourse when she said:

The surgery might be the right thing for some women (...) I couldn't go through with it. I feel like a bit of a coward but it's a very, very personal choice and (...) the doctors don't always get it right. Hopefully someone or something is watching over me and I'll be okay.

At this point, Pauline appears dissenting in her story. Doctors-as-experts are credited in medical discourse with knowing the best way to manage breast/ovarian cancer risk hence by acknowledging doctors are not 'always right', Pauline resisted the authority of medicine to know what was best for her. Ann too alluded to the limits of medical expertise when she stated "there is a lot they don't know so they can't answer all your questions". Grassley and Nelms (2009) reported on women's accounts of breastfeeding and noted resistance emerged when women's personal experiences differed to those of the expert view. The limited ability of medical experts to address women's questions or concerns, and conflicts between the expert view and personal experience, led to resistance and validation of personal explanations of why things happen as they do.

Positioning oneself in opposition to medical discourse is one of the strongest positions of active agency people can make when deciding upon anti-cancer interventions (Bishop & Yardley, 2004) because those who decline may be labelled as 'difficult' or 'non-compliant' rather than considered as active and informed (Frenkel, 2013). Frenkel (2013) further argued personal values and beliefs influenced decisions about cancer

treatment more than medical evidence but that medicine was resistant to those who refused conventional approaches based on personal understandings. Resistance emerges then when those who exhibit an opposing stance to the expert view draw on counter discourses to challenge the medical discourse and validate their individual understandings. In this study, perceptions of medical knowledge as limited, uncertain and incomplete challenged the appropriateness of RRS as a strategy to manage risk and corroborated the decision to say no. Ann's story also exposed uncertainty, this time through acknowledgement owning a BRCA1/2 mutation did not make cancer inevitable:

If I had cancer, then obviously I would not refuse surgery. But I still might not get it [cancer]. Having the gene doesn't make it 100% you will get cancer (...). I guess I do believe in fate, what's for you won't go by you, yes I think it all comes down to the hand you've been dealt.

The interpretation offered here posited Susan, Rosie, Pauline and Ann took an opposing stance to the contemporary public discourse on breast/ovarian cancer risk which is underpinned by a belief genetic knowledge is a means of providing certainty and control over cancer (Claes et al., 2005) because a person's future can be defined and predicted (Paul et al., 2014) and appropriate steps taken to reduce risk (Ilkilic, 2009). To this end, the experiences of Susan, Rosie, Jacqui, Ann, Mary and Pauline signalled a point of resistance to the dominant way of thinking about risk. Their alternate understandings of what risk means reflected what Paul et al. (2014, p. 82) referred to as the "captious certainty" of genetic information. Genetic knowledge has an aura of certainty but in reality it is similar to other forms of medical knowledge in that it is incomplete, changing and at times inconsistent. The promise of certainty is therefore captious as it may lead to more rather than less uncertainty about one's situation, as the participants' stories showed.

Resistance to the dominant risk discourse was also demonstrated through ways in which the objective, factual nature of statistical calculations was challenged. Pauline said:

(...) eventually the result came back as BRCA 2 positive and they told me my chance of getting breast cancer was about 50% and for ovary cancer, about 15%, much higher than normal. I feel a bit silly admitting this but I thought the risk would be higher, like 100%. So yes it's higher than if I didn't have the gene, but it's still not 100%. I thought if you had the gene, you got it [cancer] which was the first shock. Then I find out even having them take away your breasts and ovaries, you can still get cancer (...) and you are higher risk of other cancers like skin cancer. It was like opening a can of worms. They brought up stuff I hadn't even thought about. It was totally nerve-wracking.

Like Susan, Rosie and Ann, Pauline articulated some uncertainty about what her risk meant. She acknowledged RRS did not always prevent breast/ovarian cancer but she assumed a different subject position by framing her risk as being 'not high enough' to justify surgical intervention. This demonstrated Pauline's understanding of her risk was inconsistent to and challenged the level of risk assigned to her through objective risk calculation.

Considerable attention has been paid to the importance of the meanings people attach to risk. There is compelling evidence that genetic knowledge does not necessarily alter personal risk perceptions (Braithwaite et al., 2006; Heshka et al., 2008) and perceived risk is more important than objective risk in decision making about RRS (Hoskins et al., 2012; Witt, 2013). In women newly diagnosed with breast cancer, Citrin et al. (2012) found refusal of conventional treatments was associated with a perception treatment was riskier than no treatment/non-conventional treatments, irrespective of the strength of supporting evidence. Indeed the strength of medical evidence in support of RRS may be largely irrelevant to women because fear and worry can lead to an over-estimation of risk which is more meaningful to women than objective risk (Rosenberg et al., 2013). It is also widely acknowledged that differences exist between scientific and lay understandings of risk (Ahmed et al., 2012; Hoskins et al., 2014; Paul et al., 2014;

Wagner, 2011) yet in the medical arena, objective measures remain central to decision making and personal meanings of risk are largely ignored (Dauer et al., 2011; Ilkilic, 2009; Wagner, 2011). Certainly Pauline would be considered high risk in clinical guidelines for the management of HBOC (for example, NICE, 2013 and Cancer Australia, 2011) hence the personal meaning she attached to her risk appeared instrumental in allowing her to adopt an alternate subject position which resisted the need for RRS. Mary also challenged dominant ways of thinking about risk:

The other thing was, they said with the gene fault the risk of cancer is really high. (...). 10 times higher than for other people, which made me think "well if it's so high, it might happen anyway", and they couldn't say "no, it won't happen". So even with it [RRS] there's no guarantee. Having this gene means there is a good chance of me getting cancer any way you look at it.

Mary said no to RRS on the grounds of risk but from a different perspective. Unlike Pauline who perceived her risk estimate as 'not high enough', Mary perceived her risk of cancer to be so high she was powerless to control it through RRS. Mary's story continued as she acknowledged the uncertainty attached to her life despite knowledge of her BRCA1/2 status:

There's no guarantees for any of us. I might get cancer or I might not. You might get it or you might not. I might have a stroke or get hit by a bus. (...) I think maybe because I smoke I don't expect to live to a ripe old age anyway.

Mary identified herself as being at risk through smoking and other risks to health which were for her, as meaningful as her cancer risk. Thus, perceptions of risk were exposed as deeply personal and experienced in resistance to statistical, objective measurements. It was evident Susan, Rosie, Jacqui, Ann, Mary and Pauline came to see genetic risk as uncertain and medical knowledge as unstable. Their divergent meanings of risk suggested high risk women may be confronted by similar challenges but internal and external contexts mediate the meanings attributed to risk and how risk is personally interpreted and understood. Although meanings differed, the participants' responses to risk converged in that all resisted the dominant thinking of risk as controllable through surgical intervention.

Resistance to the risk discourse and the illusion of certainty which accompanies it was also exhibited through reference to other meanings of life and death. The excerpts above showed how Ann believed her future was down to fate and ‘the hand she’d been dealt’. Rosie, Susan and Mary all referred to the role of chance in determining whether they developed cancer or not. Rosie also discussed her religious beliefs and how they may have influenced her decision to say no to RRS:

I wouldn’t say I was overly religious, not really god-fearing (...) but we have been brought up as church-goers. I don’t go [to church] now but my mum still does, every week. So we were brought up believing God was looking down on us and God had a plan for us all (...) it [religion] affects you more than you think, I suppose I think it will happen [cancer] if it’s what’s meant for me, you will get it if God’s wish or whatever you want to call it. What will be will be, you know?

Earlier in this thesis Jacqui described how high risk women’s breasts were colloquially referred to as ‘ticking time bombs’, something she in part agreed with whilst simultaneously acknowledging non-genetic causes of cancer:

The weird thing was, I felt a bit like it as well (...) but having them off doesn’t feel like the answer. There’s part of me thinks it’s all down to fate, it’ll either happen or it won’t. It just comes down to luck.

The analysis here illuminated ways in which Susan, Rosie, Jacqui, Ann, Mary and Pauline adopted alternate subject positions which resisted the dominant way of thinking about cancer as inevitable in BRCA1/2 mutation women and cancer risk as controllable through surgical intervention. Their stories revealed understandings about disease and death exist which were as, or more, meaningful to high risk women as genetic knowledge, but which were unaccounted for in cancer risk discourse. When medical knowledge is not seen as certain, unproblematic and fixed, high risk women may come to draw upon a number of alternate discourses to construct divergent subject positions even when these challenge the dominant way of thinking. It is the conflicts and contradictions which emerge from dominant discourses in relation to HBOC which create the space for resistance. Although various alternate positions were constructed, all participants questioned the necessity of RRS in the absence of disease.

A feminist interpretation contended saying no to surgery for cancer risk may be understood as an opportunity for high risk women to take actions other than those ascribed by the dominant medical discourse and to act in accordance with what was personally important. In this way, Susan, Rosie, Jacqui, Ann, Mary and Pauline were active in redefining medical advice by claiming expertise over their own bodies and their embodied experiences. The decision to accept or refuse RRS was more complex than medical discourse suggested (Hallowell & Lawton, 2002) and was not perceived as the solution to cancer risk. By resisting the notion of risk-as-disease, the participants were able to create personal ideologies and modes of reference which made sense to them even when these conflicted with the dominant medical discourse. However, such resistance lays women open to accusations of irresponsibility (Bishop & Yardley, 2004; Frenkel, 2013) therefore high risk women must seek alternative means of demonstrating their sensibility. Earlier Ann ascertained “If I had cancer, then obviously I would not refuse surgery”, a view shared by Rosie:

So it just seems so drastic. I *don't* [said with emphasis] have cancer (...) but you are made to feel like you do. Who is having a heart transplant because they might get a heart attack in 10 years? It just doesn't make sense when you are still healthy. It would be different if you already had it [cancer].

The subtext of Rosie's story here implied surgery would be acceptable should she be diagnosed with cancer. In this next excerpt, Jacqui also highlighted surgery as an appropriate response to the disease of cancer when referring to online chats with other BRCA1/2 mutation women:

To be fair, some of them had cancer in one breast already so you could understand it, why they would want to be tested and have the other one off. I think it's different then, you've no choice really. I can understand you would want everything away then.

It was evident Jacqui was able to rationalise the ideal subject position when one has cancer but not for cancer risk, demonstrating the same surgery acquires different meanings according to personal perceptions (Press et al., 2005). Risk discourse attempts to locate disease and death in women's breasts and ovaries in the same way

the disease of cancer does (Piot-Ziegler et al., 2010). When one has cancer, surgery is acknowledged as the appropriate response (Witt, 2013) however the participants' stories show the framing of surgery as the solution for cancer risk is resisted by some high risk women. The subtext 'I would have surgery if I had cancer' avoids accusations of irresponsibility and reinforces resistance to the discourse of medically managing risk by accepting the need for surgery should a diagnosis of cancer be made.

In the same way, Rosie, Mary, Ann, Pauline, Susan and Jacqui's acceptance of more intensive surveillance for their risk can be understood as attempts to construct themselves as sensible by acknowledging the materiality of cancer whilst refuting the materiality of risk. Hence, high risk women position themselves as active in accepting medicine's ability to attend to the disease of cancer but negotiate medicine's access to their bodies on the basis of risk of cancer.

The stories of Susan, Rosie, Jacqui, Ann, Mary and Pauline reveal how they attempted to make meaning of their experiences of risk even when discursive spaces were severely restricted. Medical discourse defined risk as something measurable, calculable and reducible, giving risk a materiality and an almost tangible aura which conflated risk with disease. Cancer risk-as-disease was a threat because cancer is deadly thus risk comes to mean premature death. However, as the participants' stories showed, risk is experienced as something out with its construction in medical discourse.

To conclude this section, Rosie, Mary, Ann, Pauline, Susan and Jacqui were unable to situate themselves within a discourse which constructed the body as diseased because they resisted the conflation of the body-at-risk with the body-as-diseased hence the removal of body parts was unnecessary and incongruous. A further point of resistance emerged through personal understandings of breast/ovarian loss which differed to

those outlined in the medical discourse. In medical discourse, the loss of breasts and ovaries is routinely attended to through surgical and chemical restoration, offering women the opportunity to reduce cancer risk whilst maintaining the body. In contrast, as the analysis in this study revealed some high risk women demonstrate resistance to the reconstruction/replacement discourse in HBOC management and create counter-discourses which make sense in the context of their personal experiences.

Resistance to the discourse of replacement

In medical discourse, RRS is understood as a beneficial process which removes risky body parts and renders the body safe, like the bodies in biomedicine (Turner, 1998). Moreover, in contemporary HBOC discourse, the loss of body parts through RRS is able to be ameliorated through surgical and chemical means. All the participants discussed breast replacement in the form of surgical reconstruction and most discussed the chemical replacement of ovarian function. It was evident breast reconstruction was framed as a routine and necessary step for women facing breast loss. For example, Susan said:

You need to see a plastic surgeon, and a psychologist. And if you have surgery you need implants, or I think they said there was other types [of reconstruction], using your own fat from your stomach, type of thing.

The analysis revealed references to the make-over metaphor (Cobb & Starr, 2012) which permeates breast reconstruction and advocates women's risky breasts can be replaced or even improved hence reconstruction is part of the package of cure for HBOC. Susan, Jacqui, Mary and Rosie all discussed being told by others, including health professionals, their bodies could be improved through reconstruction. Susan's friends suggested she would "probably look better" after surgery and reconstruction, Rosie was encouraged to "go bigger" through breast reconstruction, Jacqui's general practitioner joked she might acquire "better" breasts and Mary's surgeon commented some women "looked better" after reconstruction.

In Western medical discourse, the consistent representation of high risk women as able to be 'cured' of cancer risk through RRS and their surgically modified bodies simultaneously 'fixed' through reconstruction offers women hope they can circumvent genetic destiny and gain reassurance of future health without compromising their body. What this discourse conceals is the potential for bodies to be further damaged through reconstruction. A feminist interpretation revealed that collisions occur when personal meanings and experiences differed to dominant representations of reconstruction. Accordingly, it was evident Susan, Rosie, Jacqui, Ann, Mary and Pauline did not recognise their experiences within the discourse as presented. Mary discussed potential negative physical impacts of reconstruction:

There wasn't one thing put me off the surgery, it was loads of things. If I'm honest, I really did not want to lose them [breasts]. I wasn't keen on implants because I imagine them as cold and hard. But I think that is so. I've spoken to women [with implants] and they've said as much. Cold, hard lumps with no feeling. There's no sensation with them. But at the same time, I wouldn't want to be left like an ironing board. They said I couldn't get the reconstruction with my own muscle because I'm a smoker and it probably wouldn't take and I've got high blood pressure.

Ann also discussed concerns about implants and reconstruction using tissue transfer:

There are some safety issues with implants aren't there? Are they really safe? Why would they be trying to make new ones if silicone was safe? They did show me pictures of women who had reconstruction using their own skin and muscle but it made me squeamish just looking at them.

These excerpts further illuminated the meanings Susan, Rosie, Jacqui, Ann, Mary and Pauline attached to breast reconstruction which were discussed earlier, and confirmed that the participants made meanings of breast replacement which differed to those outlined in the reconstruction discourse. The dominant understanding of reconstruction as a solution to breast loss was resisted in favour of a stance which constructed it as a risk to the body, in keeping with research which found women's experiences of reconstruction often differed to those presented in reconstruction discourse (Koskenvuo et al., 2013; Rolnick, et al., 2007). The negative physical impacts of breast reconstruction are well recognised, the more significant of which include numbness/loss of sensation (Barton et al., 2005; Gahm et al., Hallowell et al., 2012;

Rolnick, et al., 2007), pain (Barton et al., 2005; Bresser, 2009; Gahm et al., 2010; Hallowell et al., 2012; Rolnick, et al., 2007) and infection (Barton et al., 2005; Gahm et al., 2010; Metcalfe et al., 2004). A considerable negative impact on women's lives can result owing to other adverse effects such as swelling (Metcalfe et al., 2004), lymphatic fluid leakage (Barton et al., 2005), limited arm movement (Barton et al., 2005; Hatcher & Fallowfield, 2003) and difficulty sleeping (Gahm et al., 2010; Hatcher & Fallowfield, 2003). Women also report experiencing their reconstructed breasts as 'dead' (Hallowell, 2000) and like Mary above, describe them as hard, cold objects (Löwy, 2010). Post-operative complications mean many women require multiple interventions (Barton et al., 2005; Hatcher & Fallowfield, 2003; Koskenvuo et al., 2013; Zion et al., 2003) hence it is not surprising women report feeling unprepared for the enormity of the impact of mastectomy/reconstruction (Hallowell et al., 2012; Lee, Hultman & Sepucha, 2010; Rolnick, et al., 2007).

In the discourse surrounding HBOC, it is not only breast loss which can be compensated through medical intervention. A discourse of replacement surrounds ovarian loss namely chemical replacement of ovarian function to avoid or reduce the negative impacts of premature menopause. In addition to understanding reconstruction as a risk to the body, Susan, Rosie, Jacqui, Ann, Mary and Pauline also perceived risk reducing oophorectomy to be a risk. Mary said:

(...) then if you have the ovaries out it's an early menopause, which causes problems. They also talked about tablets for hormones but I can't remember it all. Too much to take in. I mean its life changing surgery. Like I said, taking out the ovaries gives you the menopause early (...) which then means you then need to take HRT [hormone replacement therapy]. But then it can give you breast and womb cancer (...) so you have to worry about those too. It's too much to take in really.

Earlier, Mary articulated her concerns about breast implants and her disquiet about chemical replacement of ovarian function was evident here. It was clear the potential adverse impacts of both ovarian loss and hormone replacement therapy has been

outlined to Mary in medical consultations and she appreciated RRS is “life changing”. Similarly, Susan, Rosie and Pauline were also aware of the potential negative impacts on their bodies which might follow RRS:

And if you have surgery you need implants and hormone tablets which can cause breast cancer (...) which was strange. How can they give you something to make you not get cancer then give you something which means you might? (Susan)

You can get HRT but then it is linked to other cancers. I just didn't think it was right, for something you never know, might not happen [ovarian cancer]. It's like sorting out one problem then bringing on a new one. (Pauline)

I wasn't planning any more [children] but at the same time we hadn't ruled it out, it just hadn't happened. But I might have been a mother again. I'm not even 40 yet. I didn't want to turn into an old woman before my time. Taking the ovaries away brings on the menopause and you get all those problems. The sweats, the weight gain, the hair thinning. I'm just not ready for it, especially when I don't have cancer. (Rosie)

Like RRM, the potential adverse effects of RRSO are well documented. Risk reducing oophorectomy is associated with potential serious impacts including urinary tract damage (Guillem et al., 2006; Kauff et al., 2002), bowel problems (Kauff et al., 2002), pain/discomfort (Fang et al., 2009; Madalinska et al., 2005; Michelsen et al., 2009), and vaginal atrophy (Guillem et al., 2006). Following risk reducing oophorectomy, the abrupt decline in oestrogen gives rise to additional psychosocial impacts including sleep disturbances (Bonadies et al., 2011; Tollin, 2011), cognitive changes (Guillem et al., 2006; Taylor, 2001), weight gain and change in body shape (Bonadies et al., 2011; Hallowell et al., 2012). Sexual activity may be negatively compromised as a result of vaginal dryness (Bonadies et al., 2011; Fang et al., 2009; Finch et al., 2011; Robson et al., 2003) and dyspareunia (Bonadies et al., 2011; Fang et al., 2009; Finch et al., 2011; Hallowell et al., 2012; Madalinska et al., 2005; Robson et al., 2003). Oestrogen deprivation may also shorten lifespan because of an increase in onset and incidence of cardiovascular disease (Guillem et al., 2006; Sharma, 2011) and osteoporotic fracture (Cohen et al., 2012; Guillem et al., 2006; Sharma, 2011; Taylor, 2001).

In medical discourse, further medical intervention in the form of hormone replacement therapy (HRT) seeks to alleviate the negative impacts of risk reducing oophorectomy. HRT is associated with a reduction in menopausal symptoms and confers benefits to cardiovascular and bone health (Bresser, 2009; Rebbeck et al., 2009). However, evidence regarding the safety of HRT in high risk women is inconclusive. Whilst some studies have reported an increase in breast cancer risk (Beral et al., 2011; Fournier et al., 2005) others have not demonstrated such an association (Challberg et al., 2011; Domcheck et al., 2011). Additionally, there is no consistency in study design and no randomised trials hence the evidence to date is of varying quality (NICE, 2013) and remains inconclusive as to whether HRT in this group of women is beneficial or harmful (Madalinska et al., 2006; Rebbeck et al., 2009).

The lack of robust evidence on the safety of HRT following RRS means NICE (2013) have not made specific recommendations but rather advise that all women facing premature menopause should be informed of the risks and benefits of HRT and decisions made according to individual circumstances. Whilst it could be argued this facilitates autonomy and personal decision making, it could equally be argued this presents a dilemma to high risk women since as the participants' stories showed, decision making on interventions which could harm is problematic when there is a lack of evidence to support their use. Again attention is drawn to the point that these women have no disease, yet they are expected to submit to extensive and potentially harmful surgical and medical interventions, even when gaps exist in safety and efficacy data.

The reconstruction discourse is significant in the experiences of high risk women as it presents reconstruction in ways which encourage acceptance. The discourse is aimed at all women and promotes a particular vision which is typically viewed through a male lens (Rubin & Tanenbaum, 2011) and bound to norms of feminine embodiment which

are fundamentally tied to female breasts (Ehlers, 2012). Women's bodies are reconstructed primarily in ways which appeal to the male gaze, as evidenced by a focus on a woman's outward appearance (Báez-Hernández, 2009) and body symmetry (Piot-Ziegler et al., 2010) resulting in a need to "hide and fake" breast loss (O'Neill, 2013, p.17). Equally, oophorectomy is consistently referred to as more acceptable and less troublesome than mastectomy because it is less disfiguring (Claes et al., 2005; Dagan & Goldblatt, 2009) despite the potentially serious negative physical and emotional impacts on women's health. A fixation on how women *look* rather than how women *feel* conceals the many meanings women attach to their breasts which are not addressed in reconstruction discourse. Earlier, Jacqui explained the importance of her breasts in terms of how attractive and desirable she perceived herself to be. Her story continues as she discusses another important meaning attributed to her breasts:

I breast fed mine [children] and I loved every minute of it, not, not like some [women] who couldn't take to it or find it too hard. I just loved it, it made me feel like a proper mum, so it wasn't like a big sacrifice or anything. So they are important (...) they're not just lumps of fat or whatever.

The stories of Susan, Rosie, Jacqui, Ann, Mary and Pauline serve as poignant indicators of the difficult decisions women at risk of breast/ovarian cancer face. In medical consultations, the focus is on attempts to lower risk therefore much of the talk surrounds gene faults, statistical calculations, risk estimates, surgical procedures and reconstructive techniques. In RRS consultations, talk centres mainly on the more tangible or technical aspects of surgery such as risk reduction and surgical options, with less emphasis on psychosocial impacts such as impact on sexuality, libido and body image (Bonadies, Myer & Matloff, 2011). What may be lost in such consultations is the importance women place on their breasts and ovaries as essential parts of self-identity (Hallowell et al., 2012). Piot-Ziegler et al. (2010) found breast loss was a traumatising experience for women which led to a negative body transformation and challenged self-identity. Reconstructed breasts were perceived as objects which allowed women to appear 'symmetrical' and outwardly 'normal' and hence to maintain

their social appearance, suggesting some comfort was taken in conforming to normative female standards. Overall however, women experienced their reconstructed bodies as challenged, strange and lacking, because crucially, reconstructed breasts were not *their own* breasts. Earlier Mary discussed her concerns breast implants would be ‘cold, hard lumps’ and that she was not a candidate for autologous tissue transfer. Her story continued as she explained how her somewhat ambivalent feelings towards her breasts changed when confronted with breast loss:

It’s funny in a way because I’ve had a thing about my boobs since [having] the kids. They were huge when I was pregnant and they never really went down again. I must have been a double G or something then and now they are still probably an E cup. I’ve actually been going on for years before all this about a [breast] reduction. Then of course when faced with surgery and the thought of losing them, suddenly they seemed okay, great even. I became really attached to them. You start to be very conscious (...) of them being there, a part of you. Then knowing you won’t have them anymore, you really think about what a horrible loss it would be.

Although Mary was dissatisfied with her breasts, she came to value her breasts as an important part of her self-identity, a part of *her*, and it was clear reconstruction did not offer a satisfactory solution to breast loss. Rosie previously also articulated ambivalent feelings about her small breasts and in this section, her story revealed how she was advised reconstruction could enhance her body by providing her with bigger breasts. Her story continued as she shared the primacy of her breasts to self-identity, equating breast loss with losing part of her personhood:

When people ask me, they don’t anymore but at the time, why I decided not to have the surgery, there’s not one specific reason. It was just something so, what they were suggesting, just felt a step too far. I just couldn’t see myself with no female bits. They [breasts] don’t need to be big to be beautiful. I used to say, “small but perfectly formed”. So I had nothing to lose outwardly, in a sense. But I know you lose all sensation and I wouldn’t want that. It’s more than how you look. I had to get a big mole cut off once and I had wanted it off for ages, it kept catching on my clothes. But when it wasn’t there anymore, that bit of me felt strange. Not bad strange, just different. I would run my finger over my skin and think “it’s not there anymore”. And it was just a mole (...) I’d been wanting rid of. And I thought, “Rosie if your body feels different after a mole, how are you going to feel with no breasts?”

Here Rosie emphasised how breast loss compromised body integrity and self-identity by drawing on her experience of losing a mole and describing breast loss as being more than 'looks'. Although the mole was bothersome and it was removed at her request, Rosie's story suggests it left a space which made her body feel different; causing her to call into question her sense of embodiment should she lose her breasts. Hence, Rosie demonstrated an acute awareness of the biographically disruptive nature of RRS, because women experience being a body as well as having a body (Hallowell & Lawton, 2002).

Applying a feminist lens, in this study, underscored the enormity and complexity of decision making around RRS and suggested as Rolnick et al. (2007) contended, reconstruction fails to deliver the promise of normality and wholeness women facing breast loss may anticipate. Breasts were seen as more than aesthetics and were deeply connected to the sense of self and body awareness. However, body appearance was also important and the stories of Susan, Rosie, Jacqui, Ann, Mary and Pauline all reiterated the importance of breasts and ovaries as defining features of femininity and sexuality. Ann referred to her husband as a 'boob man', explaining her breasts initially attracted him and her pride in her breasts which had 'aged well' and still looked good. In this excerpt, Ann struggled with the illogicality of breast loss for risk and reaffirmed the importance of her breasts in her life:

The whole surgery thing just didn't sit well. I just couldn't imagine what it would be like to have no breasts when I didn't need to. They were not cancerous (...) and I've never been a fan of implants. I would not like them [implants] but I wouldn't want to have nothing. (...). I'm not vain but I do worry about my looks and my breasts are an important part of how I look. I know he [husband] would still love me, he's not like that, fickle, but I think losing them would really affect my confidence and our relationship because of how I would feel even if he was okay about it.

Ann acknowledged she was more than her breasts but at the same time, she was unable to comprehend giving up her breasts for risk. Her perception she 'didn't need' to lose her breasts suggested mastectomy may be 'needed' or logical should a woman

have cancer. Interestingly, Pauline used very similar words to refer to the potential loss of her breasts:

With the breasts you can get a reconstruction but even the good ones they showed me pictures of didn't look very good. I know it sounds big headed but I think I have a really good figure for my age. I like my body just as it is and I just wouldn't feel right without breasts or with implants (...) having no breasts really scares me, I'm not afraid to admit it. I am happy with me, I don't want to lose a bit of me if I don't need to.

For Pauline, her breasts were important to how she looked and to her personhood, describing her breasts as a 'bit of her' and constructing her breasted body as a source of happiness and contentment. Having no breasts threatened this sense of body wholeness and for Pauline, reconstructed breasts were not an acceptable replacement. Like Ann, Pauline constructed breast loss as something which was needed or not; indeed Pauline drew distinction between her position and that of her affected sister who had undergone mastectomy: "But the difference is she's got cancer, she *needs* (said with emphasis) to have it done", supporting the earlier discussion which framed surgery as necessary for cancer but not for risk. Mary also alluded to a perception of surgery as unnecessary in the absence of disease, tying this to the uncertainty she experienced when making her decision:

You'd ask one question and the answer would bring up loads of other stuff you hadn't even thought about. I swung from thinking, "I should have this done [surgery] because it will really lower my risk" to "this is mad, I'm having this done and there's nothing actually wrong with me!"

The inter-relatedness between risk and replacement discourses in the experiences of Rosie, Mary, Ann, Pauline, Susan and Jacqui was evident. It may be some high risk women are unable to position themselves within the reconstruction/replacement discourse in part because they have already resisted the risk discourse. When surgery is understood as a means of managing disease but not risk, reconstruction/replacement is unacceptable, even inconceivable, because surgery is 'not needed'. In this case, the negatives of reconstruction/replacement are likely to dominate as there is no perceived gain from losing one's breasts and ovaries. Or it may be those who align with the risk discourse are more able to accept

reconstruction/replacement because of a perception of breast/ovarian loss as being 'needed' to manage risk. A third position may be those who are able to position themselves within the reconstruction/replacement discourse and perceive their bodies as potentially improved through reconstruction, are more able to rationalise surgery as a suitable solution to cancer risk. It is not possible to say which of these positions is most likely for high risk women however what was evident is multiple resistances emerge as a result of competing discourses which play out in the contested landscape of HBOC management.

The stories of Susan, Rosie, Jacqui, Ann, Mary and Pauline revealed that whilst high risk women's breasts are constructed in HBOC discourse as risky, the qualities of breasts as a source of femininity, sexuality, nurturing and self-identity were equally or more important to women. By emphasising the personal importance of breasts and rejecting reconstruction/replacement discourse, the participants resisted a discourse which advocated their treasured body parts were easily replaced and exhibited an alternate position in which they were free to keep their bodies intact. Resistance was possible because these women wanted to keep *their* breast and ovaries in spite of their cancer risk hence their experiences contrasted with the usual sequence of events outlined in medical discourse.

From a feminist perspective, fighting back (Gotfrit, 1991) against the dominant way of thinking about RRS represented a strength in high risk women to challenge the dominant discourse and keep their still-healthy bodies intact. However, this was juxtaposed against the opportunity to undergo a procedure which may prevent cancer and free a woman from worry, hence resistance presents a dilemma. The strength of dominant discourses in Western society and the conflicts and contradictions inherent to them mean women are not free to choose or free to refuse because their choices are made within cultural frameworks and prevailing power relations. In Western society,

high risk women receive many mixed messages which simultaneously require them to both own and remove their breasts and ovaries hence resistance will always be negotiated and never complete.

Resistance as incomplete

The stories of Susan, Rosie, Jacqui, Ann, Mary and Pauline revealed ways in which they resisted the dominant way of thinking about HBOC risk as something which could be effectively and expediently managed through RRS. Their multiple and varying perceptions on what led them to say no to RRS suggested resistance was shaped by the cultural contexts in which cancer risk was lived and experienced. For Gotfrit (1991, pp. 176-177) “lived culture is a terrain of contradiction where dominant ideologies and practices are contested as well as produced”. Accordingly, breast/ovarian loss is especially problematic for BRCA1/2 women owing to the social investment made in women’s bodies but as the analysis showed, the decision to accept or refuse RRS is more than a simple dichotomy of following or not following codes of female normativity.

This study confirmed living with a BRCA1/2 mutation is a complex, emotional and challenging journey irrespective of whatever decisions are made with regards to managing risk. Rosie, Mary, Ann, Pauline, Susan and Jacqui took control over their own bodies, an action which is fundamental to any notion of resistance (Allen, 2014; Gotfrit, 1991, 1992) but by demonstrating resistance, they encountered other risks to self. It was evident the decision to say no to RRS was not a liberating moment in part owing to the inability of loved ones to accept this decision. Pauline discussed how her husband, despite encouraging her autonomy, was unable to accept her decision which led to a break down in an important part of their relationship:

John doesn’t like to talk about it. He said the decision was made so there was no point in discussing anymore and to be honest, I got drained talking about it, thinking about it constantly, all the time. It’s sad really because I used to think we could talk about anything, face anything together, but no. He just couldn’t accept it I suppose, even

though he said “it’s your decision”, he still couldn’t agree with it. Yes, I didn’t that see coming (...) the loneliness from feeling like you are on your own.

Pauline appears to have experienced a sense of isolation and perhaps alienation because her decision was not understood by her husband. Similarly Rosie’s story suggested she experienced feelings of isolation which were also particularly evident when discussing her husband’s reaction to her decision to say no to surgery:

It was really difficult to get Tom [husband] and Jane [friend] to understand and there were a few heated discussions, I can tell you. Jane eventually came round and I could talk to her. She said as long as I was happy, well not happy, but happy with my decision, she could go along with me. But Tom, he’s a different story. He struggled to understand my decision and we couldn’t talk about it without arguing, well he couldn’t, so we just stopped talking about it. I wanted to talk about it, don’t get me wrong, but it was just easier not to. It became natural just to bottle things up (...) I couldn’t say “I’m having a down day today” or anything. He might say “well you should have thought about that before”.

Jacqui also described her sense of isolation in the family as her thoughts and feelings about her genetic status and about RRS differed to those around her. Her story continued as she discussed her emotions when she was confirmed as owning a BRCA1/2 mutation whereas her sister Joanne was mutation-negative:

Beth [affected sister] got hyper-excited about it, going on as if everything was all okay and my result got a little side-lined I think. So I was left feeling alone, not really able to talk about it, it would have been as if I was being really negative and not sharing Joanne’s [sister] good news. It was also, the fact everyone was being all positive and “it’ll be alright” about me when they did discuss it. It was as if now I knew I could have the preventative surgery and hey presto! [raised voice]. (...). I pulled back from everyone and stopped talking about it. Just kept my thoughts to myself and told them what they wanted to hear. But mentally the impact was huge, it just left me feeling totally drained and lost (...) and alone. The whole thing is a very isolating experience. It can tear families apart.

The participants’ stories illuminated the power of genetic information and the strength of the medical discourse for cancer risk. How to attend to risk becomes the subject of extensive family debate, endlessly discussed and perhaps even argued over, which may lead to family discord (DiMillo et al., 2013; Eijzena et al., 2014). In saying no to RRS, Rosie, Mary, Ann, Pauline, Susan and Jacqui made a decision which was right

for them, but it was a decision which caused a degree of upset and disharmony in their families and left them feeling isolated and alienated. Hence as Gotfrit (1992, p.121) stated, resistance can be “incomplete, ill-conceived, contradictory, inconsequential and even damaging”.

Rosie, Mary, Ann, Pauline, Susan and Jacqui did fight back against the dominant way of thinking about managing cancer risk but they were unable to feel confident and secure in their decision and in this way, their resistance was incomplete. Perhaps not surprisingly then, they were themselves confused at times by their decision to say no to RRS and admitted to some uncertainty as to how they would deal with risk in others.

Jacqui talked of the possibility of her daughter owning a BRCA1/2 mutation:

My daughter is 18 in less than a year and she's wanting tested. She can't understand why I don't have the ops, but she's young and she hasn't had a chance to really think about the consequences. Of course I hope she won't need to, there's a 50 50 chance of her not inheriting it, which is how I try to think of it, be positive. I don't know what I will do if she does have it. Funny thing is I'm not sure I won't encourage her to have the ops if she does have it [gene fault]. I know it's like having double standards, but maybe I just want her to be safe, you know, to protect her? The worst bit about this whole thing is, you just don't know what to do for the best. It's a bit of a no-win situation.

Jacqui herself acknowledged the contradiction apparent in her story but put this aside and instead emphasised her desire to protect and ‘save’ her daughter. Jacqui’s stance here can be understood as an act of incomplete resistance and compromise whereby she was able to meet the requirements of a good mother by protecting her daughter from cancer despite resisting surgical intervention on her own body. Westfall and Benoit (2008) found pregnant women identified as ‘high risk’ demonstrated various modes of resistance to medical discourse and the medicalisation of pregnancy, from out-right non-compliance to partial compliance whereby elements of the ‘high risk’ role were adopted as a compromise to meet the demands of competing discourses on childbearing. Since women are socialised within the dominant culture and the available modes of meaning, it is not possible to escape all traditional norms and expectations

(Gotfrit, 1991), hence resistance may be incomplete as high risk women negotiate the competing demands placed upon them. The primary requirement of women to be protectors of the family (Acero, 2012) means there is limited discursive space in which to challenge and completely dismiss medical discourse when children are at risk.

Susan said:

I've talked to Emma and she knows I am at high risk and one day she'll need to get tested to see if she is a carrier and needs anything done. I suppose it does include surgery, it would be her decision and of course as her mother, I'd support her. She's still too young to take in all in but I think she understands why I've gone this way [saying no to surgery]. I try not to think about her having it, it's too upsetting. Overall I think I am okay with it all then at times I just wish we'd never been tested then I wouldn't have had to make a decision because there's not a day goes by I don't think, "have I done the right thing"? I really have to force myself go for the scans. I hate it. Every time you go you are thinking "is this the day it's going to be discovered?" It's always at the back of your mind. I think that's what makes it so hard for people to understand why I'm not having the surgery (...) not sure I understand it myself. I just know for me it's not the right thing to do.

Susan's story here reflected several elements of communal folklore in HBOC discourse. Despite Susan's regret at being tested, she positioned her daughter as 'needing' to be tested so she could potentially undergo surgery should she own a BRCA1/2 mutation. Susan reinforced the requirement for autonomy by highlighting it would be her daughter's personal decision and she, as her mother, would support this decision. This suggested in spite of Susan saying no to RRS, her personal perceptions and evaluations were insufficient in justifying her decision because she was unable to discount this for her daughter. The ability to resist dominant ways of thinking in popular and health care culture may be critical to women maintaining a sense of well-being (Grassley & Nelms, 2009), however as the analysis in this study showed, resistance itself can be a risk. Dominant ways of thinking about cancer risk may be so persuasive, even when women are able to demonstrate resistance, it is not without conflict and it is often incomplete.

It was also evident from this excerpt Susan continually questioned her decision to say no to RRS and lived with uncertainty on a daily basis, the fear of cancer never far from her mind. DiMillo et al. (2013, p. 128) found women living with BRCA1/2 mutations who did not undergo RRS experienced an “unending and uncertain process” whereby they lived constantly with the fear of cancer; the only conclusion available being a diagnosis of cancer. Ann alluded to an unending worry when she discussed there being ‘no escape’ from her risk:

I don't regret making the decision as such but I do think about it every day. And I do wonder if I should've had it [surgery]. I don't think it will ever be completely out my mind, but I am hoping it stops as time goes on and I come to only think about it rarely. Just now, it still feels a bit like there's no escape from it, especially since Gillian [Ann's daughter] will be coming up to 18 soon and she might go for genetic testing. (...) I love her so much but at times I think maybe I shouldn't have had any [children]. So I tell her to just go out and enjoy herself. I try not to stress the small things (...) maybe there's one good thing to have come out this nightmare, but truth be told, I wish the testing didn't even exist in the first place. I wish it was never invented.

Although Ann appeared to have come to terms with her decision, her resistance was incomplete as like Susan, she questioned the sensibility of saying no to RRS. A key motivator in undergoing genetic testing is the need to reduce uncertainty and cancer worry (DiMillo et al., 2013; Witt, 2013) however as this study showed, the opposite may occur and knowledge of genetic status may lead to the creation of new uncertainties and a chronicity of cancer worry. Rosie said:

It's been nearly two years [since saying no to RRS] but it's still on my mind. Have I done the right thing? It's ironic because I used to examine my breasts but I don't anymore, it's too scary. I am probably just burying my head in the sand but I don't touch or look at them unless I really have to. (...). Sometimes I regret being tested at all and think it's a really bad idea. I know I'm being selfish because, well, it's helped other women, if they've had the surgery, not got cancer. But for me it's been a can of worms. I am left with this hanging over me, like opening Pandora's box. What is it they say? She opened the box and all the bad came out but hope was left inside. It's like, hope has been, it's gone. I'm usually a positive person but it was hard to see any positives. Well it's [hope] still there but it's hard to find now. I hope for different things now, like to have a full week when I don't think about all this.

Here, Rosie's story cogently captured the uncertainty, insecurity and fear and which can hang over the lives of BRCA1/2 mutation carriers (DiMillo et al., 2013; Samerski,

2006). In this study, the act of keeping one's breasts and ovaries intact denied Rosie, Mary, Ann, Pauline, Susan and Jacqui the opportunity to reduce risk, isolated them from friends and family, perpetuated feelings of guilt and worry and left them in a state of flux as they continued to experience their bodies as risky and vulnerable.

Analysis of the participants' stories revealed the ways in which discourses of femininity and biomedicine formed an interlocking set of ideologies which served to silence their voice. Resisting RRS allows women to keep their breasted bodies intact and align themselves with normative standards which although oppressive, are none-the-less the standards upon which women are necessarily dependant for understanding their body (Ehlers, 2012). At the same time, saying no to surgery means the opportunity to be free from cancer worry and reduce cancer risk is lost and may ultimately lead to a woman developing cancer.

The conflicts and contradictions inherent in HBOC discourse means high risk women are confronted with dilemmas for which there are no wholly satisfactory solutions. Having the strength to say 'I am keeping my breasts' requires high risk women to demonstrate resistance to the socially mandated requirement to protect oneself from cancer, a position which denies the personal and cultural importance attached to female breasts and ovaries. Keeping one's own breasts and ovaries intact lays BRCA1/2 women open to accusations of foolishness, recklessness and vanity and places upon them complete accountability for a decision which may result in cancer developing. The following quote from an advertisement for the chemoprevention agent tamoxifen (taken from Press et al., 2000, p. 244) accentuates how women who care about their breasts are denigrated despite the necessity of being breasted in Western society; "If you care about breast cancer, care more about being a 1.7 than a 36B". Here, the figure '1.7' denotes a risk assessment computation with anything equal to or above 1.7 is categorised as high risk, and '36B' refers to the size of a woman's breasts.

The message here is clear: women should care more about their risk of cancer and less about their breasts. Thus, the exercise of personal autonomy conflicts with the ideal subject position outlined in medical discourse and requires high risk women to create alternate subject positions which make sense of their experiences but which may also be unsatisfactory.

To conclude this section, the analysis revealed ways, in which the participants sought to navigate, negotiate and manage the conflicts and contradictions inherent in medical discourse in the contexts of the alternate subject positions which they arrived at. However, it also suggested the alternate subject positions assumed were at times problematic and insufficient in justifying the decision to say no to RRS, such was the strength of the medical discourse, hence their resistance was an act of compromise, an incomplete process and ultimately a risk in itself.

Summary of analysis and discussion

A key argument underpinning this study was that the decision to say no to RRS for cancer risk must be understood within the context of the social, cultural and historical milieus in Western society which shape experience and direct the meanings attached to HBOC and RRS. Three literary theories were used to provide a contextualised interpretation of the experiences of six women who said no to RRS.

The application of Marxist literary theory was useful in providing an interpretation of the participants' experiences in light of dominant ideologies in Western society which shape human experience in relation to gender, sexuality, work, the family and other cultural ideals. The analysis submitted that an economic discourse underpins genetic medicine in which the 'at risk' body is conceived of as a potential source of economic gain for various stakeholders in the HBOC industry. Ideologies of risk appear to impose a genetic responsibility on high risk women making them accountable for

cancer risk in themselves and others. Additionally, ideologies of risk fragment the body and allow breasts and ovaries to be commodified as assets of varying worth which may be removed or replaced in the reconstruction marketplace. A Marxist analysis of the participants' stories revealed conflicts between interests and forces in society. The contradictions in the participant's stories were reflective of the contradictory nature of social reality, including the tension created by conflicting medical and gender/sexual ideologies.

From a Foucauldian perspective, RRS is a practice open to multiple, changing interpretations, all of which vie for ascendancy and which could equally be chosen as accurate representations at particular points in time. The analysis explored how 'the truth' about breast/ovarian cancer came to be and how this truth supported the dominant medical discourse and sanctioned surveillance strategies and risk reducing interventions to discipline the bodies of the asymptotically ill. This dominance made the participants' decisions to say no to RRS perplexing. It was evident Susan, Ann, Mary, Rosie, Pauline and Jacqui initially conformed to dominant understandings of cancer risk and RRS, but subsequently came to question the medical discourse, ultimately arriving at a decision to say no to RRS. This highlighted the possibility for resistance to the dominant medical discourse and revealed ways in which high risk women negotiate competing societal discourses to make sense of their experiences.

A feminist interpretation revealed that saying no to RRS could be understood as resistance to the official discourse on HBOC management; an action which provided the capacity to be oneself, to acknowledge the importance of one's breasts and ovaries and a desire to keep one's healthy body intact. The analysis demonstrated resistance is possible through the body and suggested high risk women were able to reinvent the risky body and subvert the construction of normalising strategies inherent in the discourse of cancer prevention. However, it was also evident that the female body

represented a contradictory site for women. In some ways, the participants demonstrated a strong sense of agency to keep their bodies intact despite the strength of the discourse of surgical intervention for risk. It took strength to challenge the dominant way of thinking and courage to keep one's body intact in the face of great opposition. However, this strength was juxtaposed against the epidemiological evidence which confirms RRS does reduce cancer risk in high risk populations, and the strength of the medical discourse which speaks in support of RRS.

Why they said no

Given the above analysis and use of the three literary lenses, this study found different understandings of risk to be central to the decision to say no to RRS. Although individual interpretations sometimes differed, the personal meanings the participants attached to risk differed to the dominant understandings of risk which permeate the communal folklore of breast/ovarian cancer and which support the medical pathway for cancer risk. The women who took part in this study said no to RRS as a result of a shared a private folklore in which:

- The genetic risk of cancer was not conflated with the disease of cancer;
- Genetics was not considered to be the only 'truth' about why people develop cancer and genetic mutations were understood as only one of a number of equally important risks to health and life;
- Medicine was not credited with knowing the solution to cancer risk;
- The risk of cancer was not understood as something which was treatable in the same way as the disease of cancer is treatable;
- The risk of cancer was not seen as something which could be controlled through RRS;
- Breasts and ovaries were treasured as vital body parts which could not be given up or replaced on the basis of risk;

- RRS was perceived as damaging the body and hence was a greater risk to self than genetic cancer risk;
- RRS simply did not make sense given no disease was present and given the risks of surgery to body and self.

Chapter summary

The analysis in this study proposes that contemporary understandings of cancer risk and how this risk should be managed are highly problematic and potentially harmful to high risk women who do not align with the views of the medical discourse. Essentially, the participants' experiences took place within a framework of technologies and disciplinary forces which did not take into account their personal meanings and contexts. This research finds that far from being the evidence-based and obvious solution to cancer risk, RRS was understood by the participants in this study to be a risk to body and self which superseded the genetic risk of cancer.

This study revealed how high risk women may be conflicted by competing and contradictory messages on how best to attend to HBOC risk. The official discourse on HBOC risk is persuasive. That is, women designated at risk need to remove healthy breasts and ovaries to avoid cancer. Simultaneously, the discourses of gender, sexuality and femininity ordained that RRS was perceived by the participants as a risk in itself, because to lose these valued organs was to damage the body and render it less valuable.

By examining high risk women's experiences of saying no to RRS this study also illuminated the significance of how such totalising, universalising discourses burden women with contradictory choices because the solution to cancer risk mimics the disease of cancer and strips the body of its essential female characteristics.

To conclude this section, this study showed the experiences of some women identified as being high risk of developing breast/ovarian cancer contrast starkly and rather poignantly with the expected experiences reinforced through medical discourse. This study highlighted the ways in which the high risk women are able to create a new space in the discourse of HBOC. To this end, the participants made meaning of their experiences through the creation alternative discourses and personal ideologies which made sense of their decision to say no to RRS. However, it was also apparent that despite making a decision which was right for them, they remained confused. At the time of writing, these women did not feel empowered because they still lived within a discourse in which RRS was necessary to protect themselves and their families from risk. By resisting the official management pathway of testing positive to BRCA mutations, Rosie, Susan, Pauline, Mary, Jacqui and Ann came to grasp the contradictions inherent within the official treatment pathway and consequently took steps to find meaning in their experiences which reaffirmed their sense of self rather than accepting their alienation from self. Paradoxically, the need to control risk through RRS as outlined in the medical discourse, exposed the women to different type of risk: loss of the embodied self.

The next section comprises the conclusion to the thesis. The purpose and aims of the study and the methodological approach taken are revisited prior to a recapitulation of the key findings. The strengths and limitations of the study are presented and recommendations for practice and further research in relation to HBOC are considered. The thesis concludes with a reflexive account which provides a critical reflection of the researcher's perspective during the conduct of the study and which, in keeping with Dolby-Stahl (1985), acknowledges the researcher's full responsibility for the final interpretations of the participants' stories as presented in this thesis.

CHAPTER 7: CONCLUSION

Introduction

This study set out to explore the experiences of women who said no to RRS for breast/ovarian cancer risk following a mutation-positive genetic test result. This research is important because it addressed an increasingly prominent and significant area of concern in contemporary health care: the care of people identified as ‘at risk’ of disease by virtue of their genetic status. Genetics means medicine is now able not only to identify those with disease, but also those *at risk* of disease, which has redefined understandings of health, medicine and the human body (Webster, 2002).

Although a relatively new branch of clinical medicine, genetics is at the centre of the public and professional dialogue on cancer (Maturo, 2012). People at risk of disease are now able to be categorised as “pre-disease” (Kreiner & Hunt, 2014, p. 870) and people who are identified as owning a genetic mutation which increases the risk of cancer may be called “previvors” (Mahon, 2011, p. 126) or pre-survivors. These new conceptualisations of health and disease mean risk is treated as a disease in itself (Moynihan et al., 2012) and medical interventions such as RRS, are able to be made on the still-healthy bodies of those at risk. This may be understood as representing a communal folklore which defines how people understand the risk of cancer and accordingly how cancer risk should be dealt with. However, despite the strength of the discourse surrounding cancer risk, some people who are identified as genetically predisposed to developing cancer say no to RRS. The purpose of this study was to explore the experiences of high risk women to illuminate an understanding of why.

Genetic medicine is a rapidly developing and dynamic field. Although a growing body of evidence in relation to HBOC and RRS is emerging, research to date has focussed primarily on interventions to manage risk and the efficacy, benefits and potential harms of such. The potential physical and emotional impacts of RRS have been investigated

but consideration of the material and social conditions which shape the everyday lives of high risk women has been neglected. Notably research into the social, cultural and political contexts within which decision making about RRS takes places is lacking. This study sought to remedy this weakness and to bring a new perspective to HBOC research by considering the positions and experiences of high risk women within the contexts of dominant discourses in Western society.

Revisiting the methodological approach

This study was underpinned by a belief the decision to say no to RRS for cancer risk must be understood within social, cultural and historical contexts in Western society which shape experience. It contended that a communal folklore surrounding breast/ovarian cancer exists, underpinned by dominant discourses and ideological practices which give consent to certain ways of acting in response to cancer risk. Likewise, a communal folklore about the female body means women's bodies are understood in particular ways in Western society, a key component of which is having breasts and ovaries. In the dominant medical discourse, ideologies of risk and treatment demonstrate that medicine has the power to prevent disease, through the practice of RRS. The decisions of high risk women to say no to RRS are thus understood to be 'anti-health' within Western medicine, but are worth considering from the interpretive assumption of the multiple truths and in the context of other societal discourses which validate the self and offer competing understandings for women who opted to say no to RRS.

This study used a synthesis of Denzin's (1989) interpretive biography and Dolby-Stahl's (1985) literary folkloristics as a framework for gathering, reading and interpreting the stories of the participants. This strategy provided a contextualised narrative of the life experiences of high risk women who said no to RRS. Foucauldian, Marxist and feminist literary theories were selected as suitable lenses through which

the participants' stories could be read and interpreted since these theories allowed a focus on the key areas of concern. Foucault's theories on discourse and power, Marx's concepts of ideology and commodification and the feminist concept of resistance were chosen as the concepts which could best explain the themes arising from the research in light of social, cultural and historical contexts in Western society.

What this study found

The findings from this study show HBOC is tainted by many discourses and multiple ideologies which as Turner (2008, p. 150) stated, are "never uniform in their effects or unified in content". The multiplicity of such discourses and ideologies allowed questions to be posed in terms of how high risk women negotiated competing and conflicting messages in relation to the HBOC journey. Unravelling the participants' stories to illuminate an understanding of why they said no to RRS was challenging because the women themselves found it difficult to understand and articulate why. Like the HBOC discourse, the participants' stories were fraught with conflict and contradiction. This was not surprising given they and their families had experienced first-hand the undesirable impacts of breast and/or ovarian cancer and its treatment. The participants faced constant exposure to the communal folklore surrounding HBOC and its management and to gendered stereotypes on what a woman is and looks like. Privately, these women feared the loss of their breasts, and to a lesser extent their ovaries, and held a belief they would be less of a woman without them. Publicly however, they were expected to put 'health before looks' and do *whatever it takes* to protect themselves and others from cancer, including removing their healthy breasts and ovaries.

The participants' stories revealed a communal folklore about HBOC existed in which RRS was a 'no-brainer', the obvious choice when one's body is at risk of cancer. It was evident that all the participants had been encouraged to think of their bodies as

'ticking time bombs' because their genetic risk for cancer was considered in the same way as the disease of cancer. Like cancer, risk became tangible: *a thing* which could take lives, devastate families and orphan children, but also something which was controllable through surgical intervention. In this context, radical interventions on their healthy bodies made sense to others. In contrast, the participants in this study shared understandings of risk which differed to the communal folklore and accordingly RRS did not make sense in their personal experiences. Epiphany moments such as being identified as a BRCA1/2 mutation carrier and saying no to RRS appeared to call into question existing perceptions of self and required these women to construct alternative discourses and modes of reference which made meaning of their experiences and allowed them the strength to keep their healthy bodies intact. However, as has been revealed, the covert power of the medical discourse remained a constant challenge to the resistance shown by participants when constantly presented with images, health advice and the reaction of family members and friends.

This research clearly demonstrated that the social reality of women identified as high risk of developing breast/ovarian cancer comprised a complex, emotional and challenging journey in respect to their decision with regards to managing risk. Their genetic status became the subject of extensive family debate, endlessly discussed and perhaps even argued over, as families and friends became concerned with their decision to say no to RRS. Their bodies were debated, examined, scanned, discussed, invaded, medicated and for some, at the time of writing, perhaps even permanently altered in the quest to reduce cancer risk. Being identified as owning a BRCA1/2 mutation placed their bodies in an enduring vulnerable and contingent state. What was discovered was that the medical discourse on managing risk through RRS was so entrenched in bringing meaning to this experience, that the women in this study were unable to fully escape its influence and reconcile with their decisions to say no to RRS. Despite demonstrating resistance to the accepted medical pathway, the

participants continued to benchmark and evaluate their decisions to say no against those who had undergone RSS and the constant pressure of family members, leaving them in an unending state of flux as to whether they had made the right choice.

Another key finding of this study was that the participants shared a genetic pessimism which negatively transformed their lives and forced an awareness of the body as dangerous and potentially diseased. Furthermore, the legacy of genetic responsibility meant the participants also experienced an awareness of their children's bodies as dangerous for which they blamed themselves, even though genes are out with personal control. It may be postulated that genetic risk is lived and understood in ways not accounted for in medical discourse: as a type of embodied risk for which there are no universal, acceptable prevention strategies. The participants were largely unable to see the benefits in genetic testing, with most stating a wish it never existed and referring to genetic testing as opening a 'can of worms' which changed life for the worse and ultimately transformed them into asymptomatic patients.

It is clear from this study that the relationship between genetic testing and cancer prevention strategies is not straightforward. Counter to the conventional view that knowledge of genetic status empowers individuals to take action to improve health and/or prevent disease, this study revealed the potential for genetic testing to disempower and cause harm. Genetic testing and RRS were exposed as biographically disruptive events for which there were no wholly satisfactory solutions, only negotiated positions which were taken up and which made sense at the time. Competing discourses allowed scope for resistance to medical discourse and showed other discourses do exist in which high risk women make decisions other than what medical experts advise. By resisting medical discourse, the participants acknowledged they were rejecting the 'normal' response to breast/ovarian cancer risk. This was part

of a reflexive process through which they came to understand themselves as individuals within multiple competing and conflicting discourses.

The competing threads of communal folklore presented the participants with a dilemma and often silenced their voice, as their personal experiences had not yet been galvanised into a private folklore of their decision to say no to RRS. Private folklore requires the sharing of stories with others having the same experience thus creating a space for the development of new understanding of an experience at odds with the communal folklore of having the genetic mutation. The effects of dominant ideologies and discourses were so strong, those who said no were dubious of their own decisions and were still dealing with the effects of a discourse which isolated them from family, friends and from each other, because a discourse of saying no was not yet established. This research is therefore a conduit for communicating a new phenomenon and the emergent private folklore of the participants represents a new way of thinking about cancer risk and RRS in contemporary health care. By saying no, the participants in this study are at the frontier of an alternative way of thinking about RRS in which high risk women are able to say no to surgery without being ostracised and in which they and their concerned others may be able to make peace with their decisions. It is these non-compliers who expose cancer risk management as a contested terrain and create the conditions in which people can restore agency and reclaim power over their still-healthy bodies. The emergence of their private folklore shows how women attempt to make sense of their experiences and negotiate the conflicts and contradictions thrown up by competing discourses, as outlined in the diagram below.

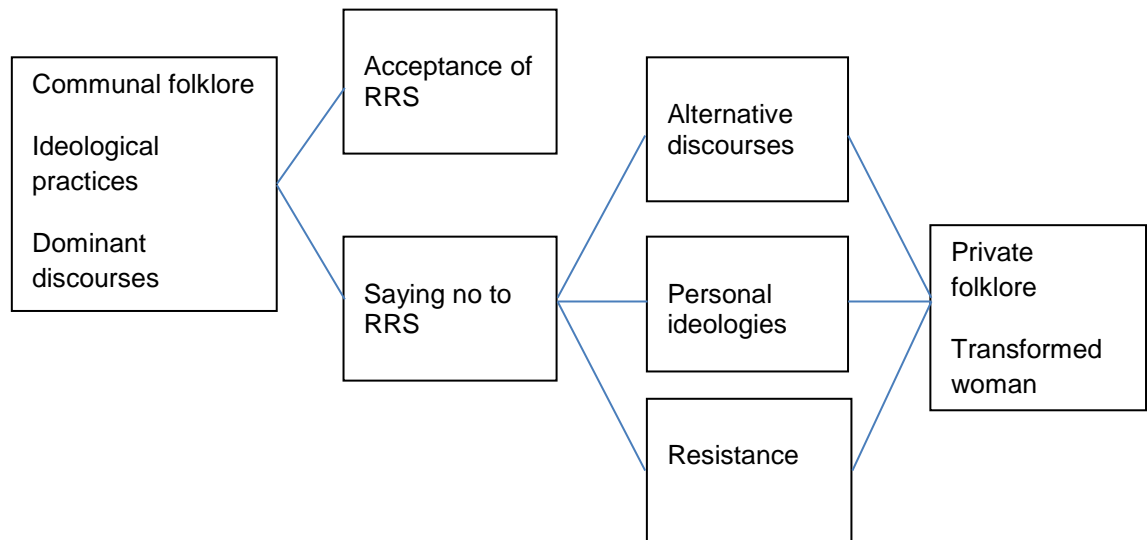


Figure 6: Interplay between the key theoretical constructs and what these mean.

To sum, this study challenges the dogma that genetic medicine is inherently beneficial and empowering and lends support to calls for more research into how genetic information impacts on the daily lives of people. The study findings are thus important and timely given the increasing prominence of genetics in cancer care, and indeed the increasing numbers of women facing decisions on whether or not to surgically remove their healthy breasts and ovaries. This study provides a means through which women who say no to RRS can know there are others who share their experience, thus legitimating their right to say no and creating an avenue for resistance, and, an emerging alternate discourse.

A closing point here therefore is that although the resistance demonstrated by the participants in this study was not complete, neither was it inconsequential. The ways in which high risk women understood their genetic risk and how other discourses and ideologies influenced decision making are important considerations for cancer prevention policies and strategies. This study advocates that rather than motivate individuals to take steps to reduce risk, the medical discourse may alienate and isolate people who do not conform to their edits and thus expose them to greater health risks.

Contribution to knowledge

This study makes a key contribution to knowledge because it problematises and challenges taken-for-granted assumptions about how BRCA1/2 mutation carrier women will respond to cancer risk. Rather than adding to the body of research which has explored the potential physical, emotional and psychosocial impacts of RRS, a particular strength of this study is that it adds knowledge about the cultural, social, political and economic implications of HBOC and RRS and focusses on the experiences of women who have said no to RRS thus giving an alternative voice to those living with experience of having BRCA1/2 mutations. Although RRS is offered and refused/accepted in the context of the medical consultation, personal and subjective contexts in which everyday lives are lived are shown to be central to the decision making process.

This study exposed the divergence between medical and other discourses in Western society which high risk women use to make sense of their experiences. Accordingly, a strength of this study is its ability to illuminate how personal, individual negotiations of breast/ovarian cancer risk are critical to understanding decision making and how these supersede factual, objective information about risk. This study also contributes to knowledge by exposing how high risk women may be denied the opportunity to reduce their risk of cancer because of gendered discourses which construct women's bodies in particular ways. Again, acknowledgement of these discourses is not well articulated in medical discourse and where acknowledgement does occur, the solutions offered are equally problematic for some high risk women.

Study limitations

The findings from this study are drawn from a small sample of women who volunteered to take part in the study. It was difficult to recruit more women owing to difficulties of access. There was no formal provider looking after the women who decided to forego

RRS, therefore access was via media advertising. Taking part in this study required the participants to make public what was privately difficult. The issues these women were dealing with including anxiety, family conflict and isolation may make this a hard to reach group who are reticent to come forward and take part in research. Indeed two participants asked to be interviewed without family knowledge owing to such issues.

This was an exploratory study in which the focus was limited to a particular group of people. The findings are thus limited to discussion of women who carried BRCA1/2 genetic mutations which increase the risk of breast/ovarian cancer who said no to RRS. The participants were interviewed at one point in time and none had received their genetic test result more than three years prior to interview. It is therefore not possible to say what the long term impact of saying no to RRS might be, or whether the participants' decisions change over time.

Recommendations

One of the aims of this study was to make recommendations for the care, counselling and support of high risk women who say no to RRS. Although health care professionals attempt to advise and counsel high risk women to make an autonomous decision which is right for them, there is evidence to suggest concealed discourses and ideological practices influence the decision making process from the perspective of both the individual and the clinician. The assumption that health care professionals are always objective and impartial in advising high risk women must therefore be avoided and it is necessary to consider the implications for practice for all women identified as high risk of developing breast/ovarian cancer, whether they say yes or no to RRS. With this in mind, the following recommendations are proposed.

Recommendations for health care professionals:

- Health care professionals involved in the care and support of high risk women should be encouraged to be reflexive practitioners to ensure they are aware of their own beliefs, attitudes and subjectivities in relation to HBOC and how these might impact on their dealings with high risk women.
- To this end, the findings from this study will be widely disseminated through publication in journals, presentation at conferences and through the researcher's professional networks and will specifically identify and encourage reflexive thinking as a way of enhancing the support given to high risk women.
- More attention should be paid in medical consultations to the subjective ways in which genetic risk is understood, interpreted and experienced by high risk women. This includes cognisance of the various resources, practices and discourses high risk women use to make health decisions and acknowledgement that even statistical 'objective' risk estimates are uncertain and unstable. Educating health professionals about the wider factors which influence risk communication is an important step towards acknowledgment that conventional risk/benefit models of communicating cancer risk, may not be helpful for those identified as high risk of developing cancer.
- Models for communicating risk information which encourage exploration of subjective elements of risk perception should be developed to provide a more holistic, person-centred means of communicating risk. For example, Dauer et al. (2011) recommend risk communication models should be cognisant of the perceptions of those making the decision, perceptions which are dependent upon emotional factors such as fear, anxiety and mood rather than objective risk estimates. Eijzena et al. (2014) also advocate the inclusion of a psychosocial assessment when communicating cancer risk, to identify issues of personal importance so that tailored information can be given which addresses the issues of

most concern rather than focussing on the communication of risk per se. The development of more holistic models for risk decision making may go some way towards ameliorating the potential negative impacts of genetic information which were evident in this study.

- Health services involved in supporting high risk women should be proactive in providing tailored support to women who say no to RRS. This may help ensure those who say no do not opt out of services, are identified quickly should cancer develop and are not made to feel blameworthy for their decisions.

Recommendations for researchers:

- Avenues for future research should be explored including studies which;
 - Identify less damaging ways of managing HBOC risk.
 - Take a longitudinal approach in which women's experiences are investigated over time to create understanding of how their experiences and decisions might change and what the impacts of these might be.
 - Develop understanding of how genetic information impacts on the daily lives of mutation carriers and their significant others, for example daughters, partners and relatives who tested mutation-negative and male BRCA1/2 mutation carriers.
 - Create counter-discourses which challenge the oppressive discourses of responsibility, positivity and concealment which surround HBOC and instead expose the social and economic forces which present HBOC and RRS in particular ways and thus limit the choices offered to high risk women considering RRS.
 - Advance a politics of HBOC which resists ideologies which silence high risk women's voices and which counteracts victim-blaming.

Recommendations for policy holders:

- These stories of high risk women who said no to RRS should be used as a valuable resource to inform and underpin aspects of care for women considering RRS. Wide dissemination of the study findings as outlined above will facilitate this. It is also the intention of the researcher to present a synopsis of the study to prominent, influential cancer charities which support women with and at risk of breast/ovarian cancer. This will allow the voices of those who said no to be heard by stakeholders who are in a position to influence the delivery of health care for high risk women.
- Support groups for those who say no to RRS should be established to help manage this group of women and allow them to seek out others and share their experiences with those in a similar position.

Reflexive account

This section is a personal statement which revisits my own reflections over the course of undertaking this thesis. It presents my perspective, both as a researcher and as a health care professional and woman who shared aspects of the participants' folk group. It is a means through which I summarise information about the methodological approach taken and my personal motivations, inflections, thoughts and feelings in relation to the study and how undertaking the study has subsequently shaped and influenced me.

My interest in hereditary breast/ovarian cancer stems back to my clinical experience as a Breast Care Nurse when I was directly involved in the care of many women with breast cancer at all stages of their cancer journey, including end of life care to those who had unfortunately succumbed to the disease. Caring and supporting women with breast cancer from diagnosis to 'cure' or end of life was a privilege: it also meant I was intimately familiar with their experiences, good and bad, and the thoughts, worries and concerns they carried. I witnessed first-hand how they struggled to cope with a

diagnosis of cancer and the impacts of surgery, chemotherapy and radiation therapy on their bodies and saw them weep over the loss of their breasts. They shared with me their fears about their sexuality and their relationships following breast loss and it always seemed to me to be hugely unjust: at a time of crisis and facing a potentially deadly cancer, these women had the added burden of grieving for the loss of a body part which was so much more than just 'breast tissue'. Often, their situation was exacerbated through fears for their daughters, increasingly so as genetic causes for cancer began to take prominence in medicine and the media. It was their predicament which ignited my interest in hereditary breast/ovarian cancer and led to this research. I sought a research approach which would allow an insight into the very real struggles faced by women affected by hereditary breast/ovarian cancer, a situation made significantly worse because it was their breasts they were giving up. A key motivator was to make the voices of such women heard, hence although my research training and experience has exposed me to a range of research methods, a qualitative approach was most suited to the study aims.

The qualitative approach acknowledges that the researcher has influence over all aspects of the research process (Denzin, 1989; Dolby-Stahl, 1985; Parahoo, 2006) hence it is important the research is presented in a trustworthy and credible way (Lincoln & Guba, 1985; Major & Savin-Baden, 2010). Cohen & Crabtree (2008) contend one of the hallmarks of good qualitative research is the researcher's attention to understanding how personal preconceptions and subjectivities influenced the research process, through the use of a reflexive journal. Many definitions of reflexivity exist (Carolan, 2003) but there is consensus it is a process whereby the researcher continually reflects upon the ways in which he or she may have influenced the research process (Parahoo, 2006). This may be in terms of the approach taken, study design employed, analysis of data and/or in the interactions between the researcher and participants (Bryman 2004). Being reflexive is a process of turning the research gaze

onto the researcher therefore this next section comprises an evaluation of my own conduct during the research. To this end, I maintained a reflexive journal which included personal understandings, assumptions and preconceptions, ponderings about the participants' experiences, insights into how my perspective may have affected the interpretations and what could be considered my own epiphany moments.

In keeping with Dolby-Stahl (1985), the reflexive process also helped with the creation of intimacy and drew me into the private folklore of the participants through the shared understandings which resulted from the dialogue between us. I have provided a summary of the steps taken to facilitate the creation of intimacy in Chapter 4 (Step 4). The participants all appeared to welcome the opportunity to tell their story someone 'neutral', that is, someone interested in their situation but with no wish to influence or criticise. Indeed, several commented that family dynamics had changed for the worse as a result of the genetic revelations and therefore they had felt at times unable to discuss their experiences with family and friends. My previous experience of working with women with cancer and their families meant I was familiar with the language used by women and the range of fears and emotions which accompany familial cancer. This had to be balanced with a concern for appearing as expert and looking for what I expected to hear in their stories. Thus I explained to the participants that whilst I was experienced working alongside women with familial breast/ovarian cancer, every woman's story was unique and it was this uniqueness I wished to capture. When listening to their stories, I consciously reflected on what surprised me and why this might be. For example, I was surprised that none of the participants spoke positively about breast reconstruction, perhaps because I have worked with many women who have had very positive reactions to reconstruction.

My reasons for undertaking this research were presented in Chapter 1. I am a nurse and academic and as such, I have been educated and socialised in a discipline aligned

to medicine and have therefore assimilated certain beliefs regarding the management of HBOC. During the course of this research, I have learned that I too have talked in support of the medical discourse. Part of the initial drive in examining the experiences of women who said no to RRS, was my belief they were unwise in rejecting a course of action which could prevent cancer and save their life. I never questioned the statistics and believed 'the facts' about HBOC and RRS were the solid, reliable truth. It was the job of medicine to help women avoid breast/ovarian cancer and part of this was supporting procedures such as RRS as lives would be saved. I realise I never fully understood the risk estimates, that RRS lowers risk in the population but not necessarily the individual, and that although RRS reduced the risk of cancer, it did not necessarily significantly add to years of life gained.

Reflecting back on my previous clinical practice as a Breast Care Nurse supporting women prior to mastectomy, I observed occasions when surgeons would, unsolicited, offer women larger/smaller breasts, 'perkier' breasts or more 'youthful' breasts through reconstruction. TRAM flap procedures used to reconstruct breasts would be described as also offering the bonus of a 'tummy tuck'. At the time, I considered such suggestions as helpful to women, a way of coping with the negative impact of breast loss. However, I am now able to see the gendered discourse which underpins breast reconstruction and how this perpetuates the communal folklore about the female body and what it should look like. Assumptions about the type of body women 'want' are in fact ideologies which may limit women's choices and create illusions of normalcy which subjugate all women. As a woman in Western society, I share similar fears and concerns regarding my body and the communal cancer folklore. I appreciate the potentially devastating effects of the loss of the breasts or ovaries and of developing a potentially fatal disease and I have pondered "what would I do if it were me?" Fortunately, the answer to this question is not for me known, although I am aware of the assumption 'sensible' women opt for surgical intervention to cure the problem.

Critiquing the medical discourse has thus been somewhat discomforting, as it has made me question aspects of my previous practice which may not have supported women facing breast/ovarian loss in ways most helpful to them. My position has moved from concern for women facing RRS, to one of unease about the uncritical acceptance of genetics as the solution to cancer and the at times cavalier attitude with which high risk women and their breasts and ovaries are treated. However, like the participants in this study, I too am unable to completely resist the medical discourse, as I remain concerned that high risk women may be risking their lives by saying no to RRS.

Concluding statement

This study has presented an exploration of high risk women's experiences which led to the decision to say no to RRS. The participants' stories were constructed as personal experience narratives which were interpreted through the lenses of three literary theories, thus offering a novel and original way of examining the subject area. The biographical approach utilised gave a voice to the participants and maintained a focus on real lives being lived by real people in the real world as their stories unfolded over time. Accordingly, the biographies of the women in this study provide the social context of being identified as high risk of developing breast/ovarian cancer and saying no to what is deemed the primary method of reducing that risk. The methodological approach taken in this study allowed an illumination of the emergent private folklore of high risk women; a folklore which was at odds with the communal HBOC folklore and the medical discourse.

The stories of the participants in this study thus revealed discourses of control and resistance. RRS has the potential to both increase and decrease the control women have over their bodies and thus potentially both secures and undermines the future. Two important questions emerge from this study which have not yet been addressed;

1. By resisting the medical discourse are high risk women risking their lives?
2. Does the conflict and contradiction apparent in medical discourse which aims to reduce risk paradoxically expose high risk women to cancer risk in an even greater way?

The participants in this study shared a genetic pessimism and while they resisted the medical discourse and kept their bodies intact, they were largely unable to transform themselves in a positive way. Their decisions to say no to RRS left them in a position of regret, uncertainty and ambiguity as they were transformed into perpetual patients awaiting their fate. However, by sharing their stories, these participants provided a means through which aspects of the inner lives of those identified as high risk of developing breast/ovarian cancer could be better understood. This in turn provides a valuable resource for informing the care and support of women considering RRS.

This study was designed to address a gap in the research relating to HBOC: decision making around RRS within the context of dominant discourses and ideologies which shape experience. No other studies have interpreted high risk women's stories about saying no to RRS using multiple literary theories. This innovative approach facilitated a detailed and close examination of the phenomena of interest and allowed the research to be presented from the perspective of the participants. The value of this study was its ability to document specific issues and challenges faced by high risk women and interpret these from a number of different perspectives. No single interpretation is able to account for the many complex and intersecting discourses and ideologies which imbue HBOC. Therefore multiple interpretations are needed to create meaning. This research has problematised the dominant HBOC discourse and alternate meanings attached to the experience of being identified as high risk of developing breast/ovarian. It will therefore generate debate on how HBOC is talked about and ultimately experienced.

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Appendix 1: Study Recruitment Advertisement

Family history breast/ovarian cancer research participants required
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A research study is being conducted which aims to understand the experiences of women who chose not to have breast and/or ovarian surgery for a high risk of getting breast/ovarian cancer. The research will involve being interviewed about their experiences and why they decided not to have surgery. The information gained from the research will be used to make recommendations for the care and support of future women facing this choice. The research is being carried out in conjunction with Edith Cowan University, Perth, Western Australia.

If you can answer yes to all of these questions and would like to talk to us, we would like you to contact us;

- I have a family history of breast and/or ovarian cancer and have undergone genetic testing which has shown that I have a gene fault.
- I have been offered surgery to lower my risk of getting breast and/or ovarian cancer.
- I have decided not to have surgery.
- I am an English speaking woman living in the mainland United Kingdom.
- I am over 18 years of age.
- I am interested in taking part in this research.

Please contact the lead researcher Doreen Molloy on telephone number XXXXX.

Appendix 2: Patient Information Sheet

INFORMATION LETTER TO POTENTIAL PARTICIPANTS



Title of study: *Saying 'no': A biographical analysis of the experiences of women with a genetic predisposition to developing breast/ovarian cancer who reject risk reducing surgery.*

Participant's summary:

This is an information sheet inviting you to take part in a research study being carried out as part of a PhD that the researcher is undertaking at the Edith Cowan University, Perth, Western Australia. The purpose of this study is to find out more about the experiences of women who have been told they have a genetic predisposition to developing breast and/or ovarian cancer and who have been offered, but have chosen not to undergo, risk reducing surgery.

The aim of this study is to find out as much as we can about the experiences people have so that we can improve the information and support given to women. Although you will not benefit directly from taking part in this research study, it may improve the care given to women in the future.

You have been asked to consider taking part in this study because you have had a genetic test and been told you have a high risk of developing breast and/or ovarian cancer, and been offered risk reducing surgery which you have chosen not to undergo. If you choose to participate in this study you will be asked to take part in an interview carried out by the researcher. The interview will be carried out at a time and place convenient for you. It is anticipated that each interview will last approximately 45 – 60 minutes and will be tape-recorded so that the researcher carrying out the study can go over and understand what you have said. The tapes will be transcribed onto paper and all material will be destroyed at the end of the study.

During the interview, you will be asked questions about your experiences of being told you had a genetic predisposition to developing breast/ovarian cancer and influences on your decision not to undergo surgery. You will also be given an opportunity to tell the researcher anything you feel is important regarding your situation. The researcher will

use the information you give to produce a report on women's experiences, which may be presented at conferences and published. You will be encouraged to be as honest as you can as your views are very important. Any information you might give will be anonymised and at no time will you be identified. Participation in the study is voluntary. If you choose to participate, you will be required to sign a form stating your consent to take part. If you would like to become involved and then decide to withdraw from the study, you are free to do so at any time without giving a reason and with no negative consequences.

Thank you for considering this request.

If you are interested in taking part in this study or have any questions regarding this, please contact;

Doreen Molloy
Lead Researcher
Telephone number here

Dr Joyce Hendricks
Research Supervisor
Room 21.454
School of Nursing, Midwifery and Postgraduate Medicine
Edith Cowan University
Joondalup
WA 6027.
Email: here
Tel: here

Appendix 3: Consent Form



CONSENT DOCUMENT

Saying 'no': A biographical analysis of the experiences of women with a genetic predisposition to developing breast/ovarian cancer who reject risk reducing surgery.

I have been provided with a copy of the Information Letter, explaining the study.

I have been given the opportunity to ask questions and any questions have been answered to my satisfaction.

I understand that participation in the research study will involve taking part in an interview which will be tape-recorded and then transcribed onto paper. I understand that the information provided will be anonymised and will only be used for the purposes of this study and I will not be identified in any written assignment or presentation/publication of the results of this study. I understand that I am free to withdraw from further participation at any time, without explanation or penalty.

I freely agree to participate in the study.

Name (Print) _____

Signature _____

Date _____

Researcher's signature _____

Appendix 4: Support Services

Support services

The following list contains reputable organisations that provide a free, confidential help and support service to people affected by cancer.

Organisation	Telephone	Website
Breast Cancer Care	0808 800 6000	http://www.breastcancercare.org.uk/
Macmillan Cancer Relief	0808 808 0000	http://www.macmillan.org.uk/Home.aspx
Cancerbackup	0800 735 0275	http://www.cancerbackup.org.je/

Appendix 5: Interview Guide

- Tell me a little about when you first became aware you had a family history of cancer.
- Were you aware cancer could run in families?
- Describe how you feel about having a family history of cancer.
- Describe what it was like to be offered a genetic test for cancer.
- What were your main concerns at the time?
- Tell me what it was like to be told you had the genetic fault and you were at high risk of developing breast/ovarian cancer.
- Explain your understanding of the options offered to you because of your genetic test result.
- Describe how you felt to be offered surgery to remove your breasts/ovaries because of the test result.
- What sorts of other things were going on in your life at the time?
- Were there other things which helped you to come to a decision to say no to surgery?
- How are you feeling about things now?
- Overall, how do you think this whole experience has affected your life?
- Is there anything else you would like to tell me about your experiences?